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ABSTRACT

Personal futures planning is a tool for fostering new ways of thinking about people with developmental disabilities. Futures planning helps groups of people focus on opportunities for people with disabilities to develop personal relationships, have positive roles in community life, increase their control of their own lives, and develop the skills and abilities to achieve these goals. It is designed to complement the Individual Habilitation Planning process. This booklet introduces personal futures planning as a problem-solving process and provides a rationale for using it and a basic understanding of its components. The first chapter overviews the process and compares this approach with methods that have been used in the past. The second chapter focuses on finding capacities in individuals and explains how the "capacity perspective" differs from a "deficiency perspective." The third chapter outlines how to plan a future and how to ensure that the plan will be implemented. Building a person-centered team to make connections in the community is the focus of chapter four. The final chapter compares the traditional Individual Habilitation Plan team approach to the Personal Futures Planning approach and demonstrates how they can be used in concert with each other. Five footnotes and a 21-item bibliography conclude the guide. (JDD)

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IT'S NEVER TOO EARLY IT'S NEVER TOO LATE

A BOOKLET ABOUT PERSONAL FUTURES PLANNING

For Persons With Developmental Disabilities, Their Families and Friends, Case Managers, Service Providers and Advocates

EC 233208

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A BOOKLET ABOUT PERSONAL FUTURES PLANNING

For Persons With Developmental Disabilities, Their Families and Friends, Case Managers, Service Providers and Advocates

Written by Beth Mount and Kay Zwernik
Reprinted by the Minnesota Governor's Planning Council on Developmental Disabilities, October 1989

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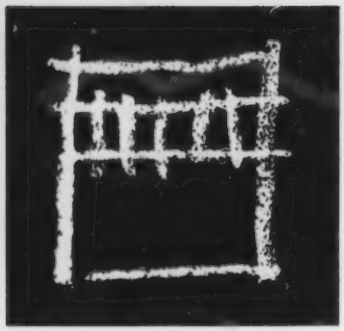

building bridges

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- Audubon School, Minneapolis
- COTA Care, Minneapolis
- Jewish Community Center
- Rustad Ceramics, Shoreview
- Taco Bell, Roseville
- Friends and family of the children and adults with developmental disabilities who participate regularly with each other in typical community settings.

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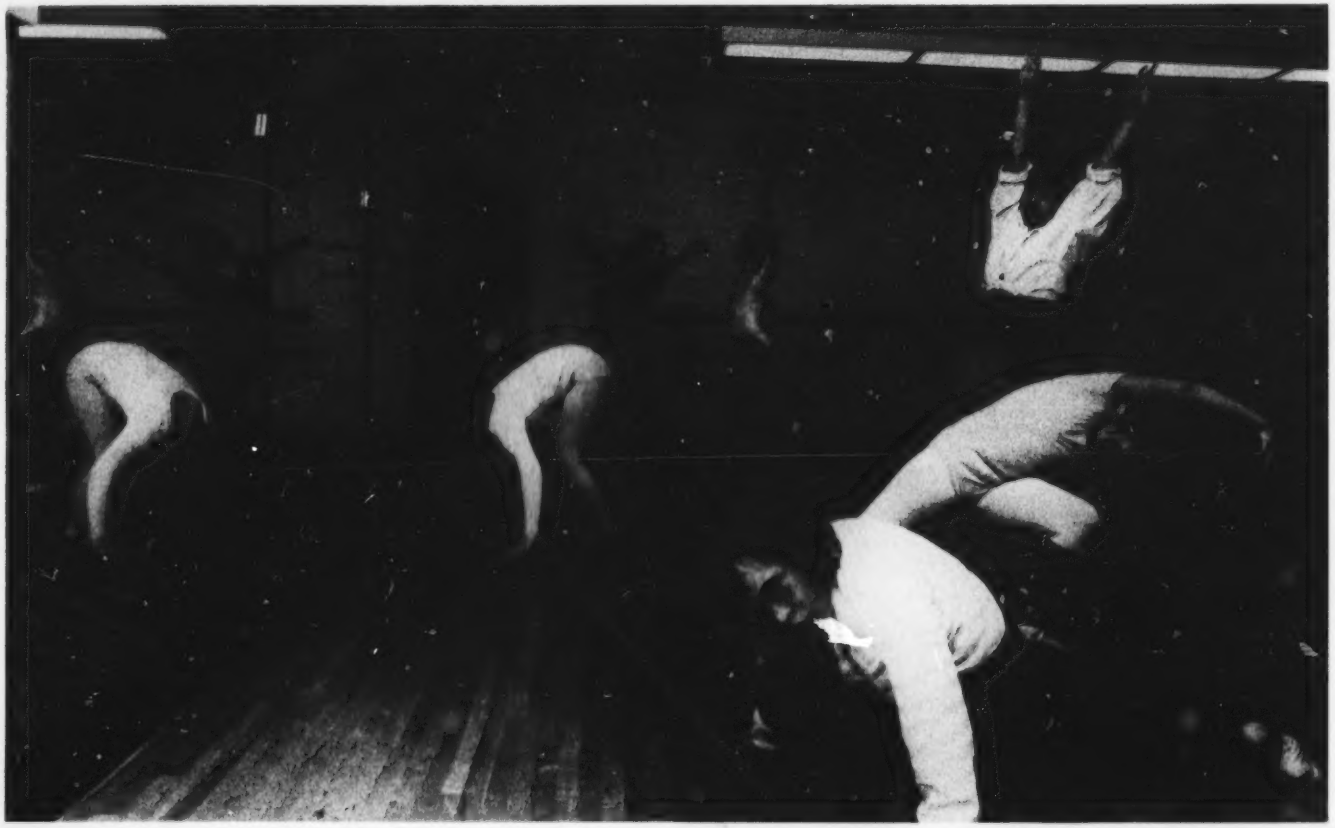
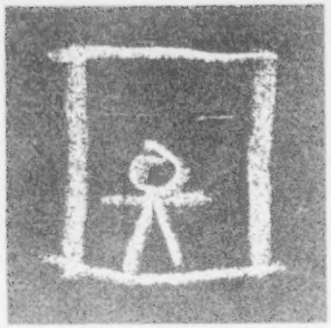
CONTENTS

	PAGE		PAGE
INTRODUCTION	1	BUILDING A NETWORK	27
A NEW WAY OF PLANNING	3	PLANNING IN CONCERT	35
FINDING CAPACITIES IN PEOPLE	9	FOOTNOTES	44
PLANNING A PERSONAL FUTURE	21	BIBLIOGRAPHY	45

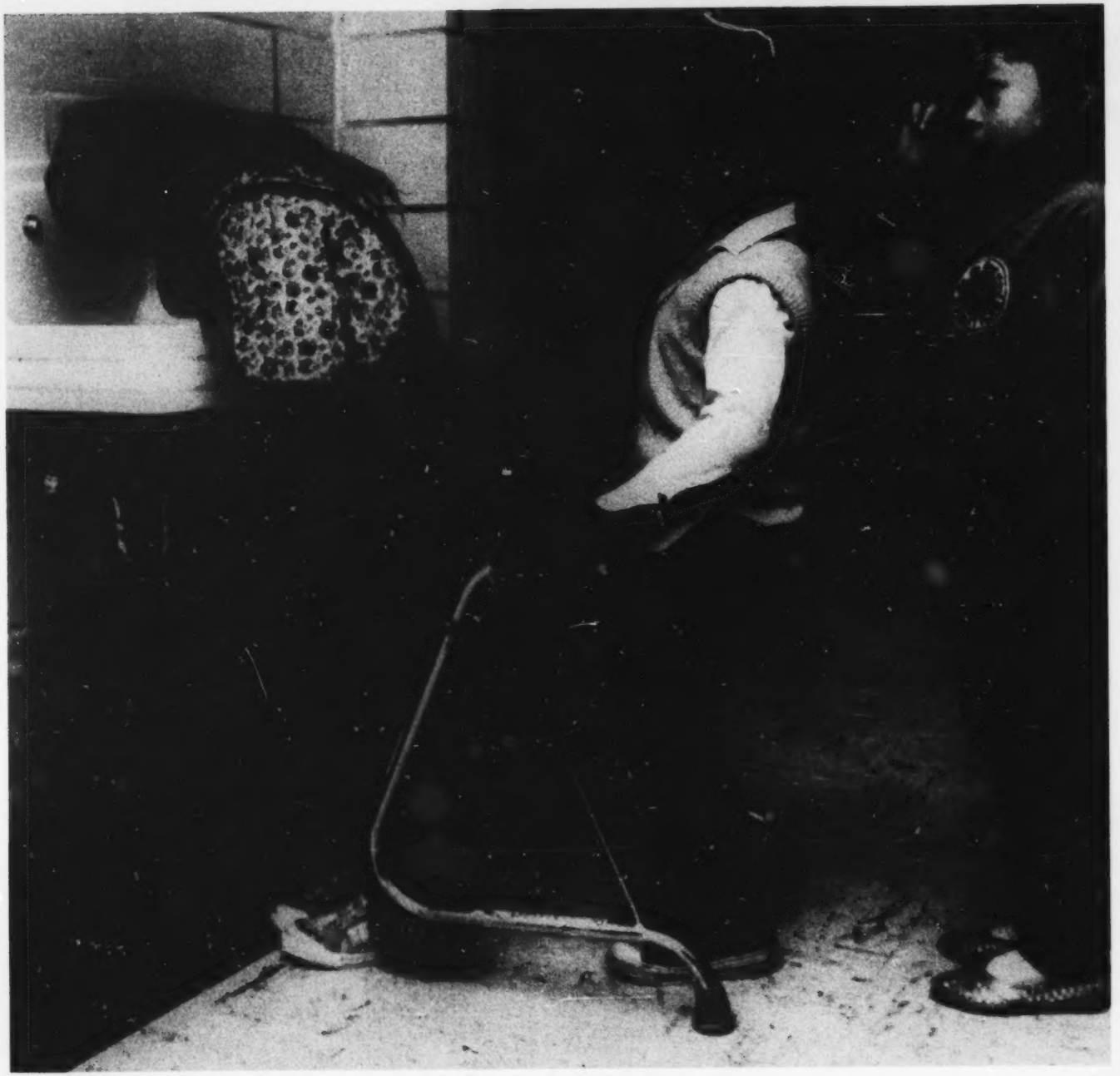
building bridges



Warm-up exercises for the integrated creative dance class.



starting small



Dane after recess with his friends at Audubon school.

INTRODUCTION

Personal Futures Planning is a tool for fostering new ways of thinking about people with developmental disabilities. Futures planning helps groups of people focus on opportunities for people with disabilities to develop personal relationships, have positive roles in community life, increase their control of their own lives, and develop the skills and abilities to achieve these goals.

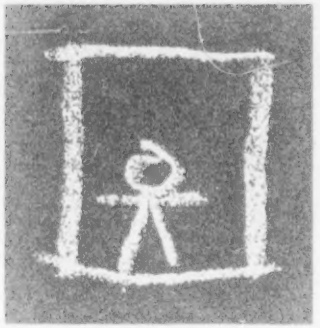
Futures planning is more than just a plan; it is an ongoing problem-solving process. It comes about through a small group of people who agree to meet for mutual support, brainstorming and strategizing. This circle of support or person-centered team makes commitments and takes action to ensure that changes will be accomplished for the focus person.

Personal Futures Planning can complement the Individual Habilitation Planning process. A futures plan can help those involved with the focus person see the total person, recognize his or her desires and interests, and discover completely new ways of thinking about the future of the person. A futures plan can lead to organizational change. The habilitation plan can help workers organize their work, and it can establish accountability among agencies for the implementation of certain strategies. Together, the futures plan and the habilitation plan provide a more comprehensive and feasible approach to achieving the desired goals of the person.

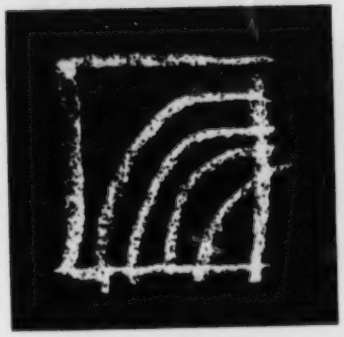
This guidebook, **It's Never Too Early, It's Never Too Late,** is an introduction to "Personal Futures Planning." It is written for family members and advocates, although others who want to know more about Personal Futures Planning will find it informative. This booklet explains Personal Futures Planning and how it is accomplished. It is not intended as instruction on how actually to do it.

The goal of this booklet is to introduce Personal Futures Planning as a process and to provide a rationale for using it as well as a basic understanding of its components. The first chapter provides an overview of the process and compares this approach with methods that have been used in the past. Chapter two focuses on finding capacities in individuals and how the "capacity perspective" differs from a "deficiency perspective," which is more common to human services.

The third chapter outlines how to plan a future and how to ensure that the plan will be implemented. Building a person-centered team to make connections in the community is the focus of chapter four. The final chapter compares the traditional "Individual Habilitation Plan" (IHP) team approach to the Personal Futures Planning approach and demonstrates how they can be used in concert with each other.



Denise and her family share a happy moment at home.



planning a future

Becky holds a pose in creative dance class.

2

A NEW WAY OF PLANNING

Personal Futures Planning has evolved from the efforts of many people working to implement the ideals of community participation for people with disabilities. Futures planning draws directly from the work of John O'Brien and Connie Lyle, community educators in human service issues, who have developed what they call "Life-Style Planning." They base it on a framework that describes five essential accomplishments that human services should seek: 1) community presence, 2) community participation, 3) choice, 4) respect and 5) competence. These will be explained in Chapter 2.

Personal Futures Planning provides strategies to increase the likelihood that people with disabilities will develop relationships, be part of community life, increase their control over their lives, acquire increasingly positive roles in community life and develop competencies to help them accomplish these goals. Futures planning helps to clarify and implement these ideals, one person at a time.

A Personal Futures Plan for a person is that person's vision of what he or she would like to be and do. When expressed and recorded, the hopes and dreams of that person become an active plan for making changes in the future. The plan is not static, but rather it changes as new opportunities and obstacles arise.

A Personal Futures Plan focuses not on deficits and deficiencies that a person may have, but rather on the person's gifts, talents and skills. This approach focuses on the positive attributes of an individual, rather than the limitations or the problems. This is very different from traditional models for planning programs and services for people with disabilities.

A basic value in this approach is being "person-centered." The focus is continually on the individual for whom the futures plan is being developed. This also is different from traditional planning methods, which have tended to focus on services and to plug a person into a slot in a program. Futures planning does not look at what services are available in the community but rather considers the things that need to happen so that an individual can fully participate in society.

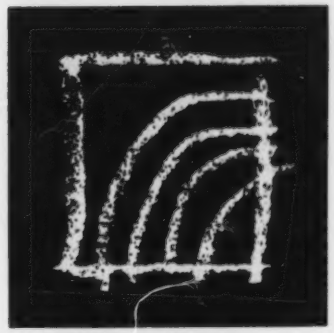
Personal Futures Planning depends upon the support and participation of a few individuals who are very close to and care about the person with disabilities. These individuals take steps to assure that things happen for the person. They help make connections in the community to assist the person in becoming a full participant in that community. This leads to a more satisfying life for the person for whom the plan has been developed.

CHANGING ASSUMPTIONS

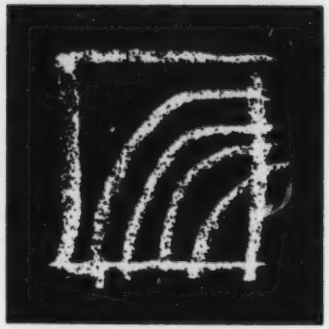
Society today sees children and adults with developmental disabilities differently than it has in the past. Many changes have occurred since the late 1960s and 1970s, when "deinstitutionalization" was in full swing. As more and more children and adults with disabilities leave public institutions or do not enter them at all, their presence in communities is being felt and seen. People with disabilities are going to school, shopping, attending church, working, playing in parks and going to the movies.

Historically, people with disabilities have been viewed as deviant and deficient—without skills and talents. Deviancy is behavior or appearance that is outside the social norm. What is considered deviant varies from culture to culture. Often the real deviancy is in the eye of the beholder. This flawed perception has been shaped by standards of acceptable behavior, cultural values, and the way these values are interpreted. In the past, behaviors exhibited by people with mental retardation have generated rejection, segregation and ridicule because the people have been subjected to doing menial or childish tasks, to inappropriate controlling techniques, or to degrading environments.

People with disabilities have been viewed as sick and having little value to society. They are diagnosed or assessed and then treated by a series of professionals in a hospital or treatment room in an attempt to "fix them." This is known as the medical model and has been the traditional model in public institutions and educational settings for people who are mentally ill, mentally retarded and elderly.



planning a future



planning a future

In the late 1800s institutions were build to house and protect persons with mental retardation from the public. The use of such institutions continued well into the twentieth century. In the 1960s, however, attitudes toward people with disabilities began to change and so did ideas about how they should be treated.

In Denmark and Sweden, efforts were being made to bring about what was called the "normalization" of people who were mentally retarded. The idea was to let these people live an existence as close to typical as possible. People with mental retardation were leaving institutions and moving into the community, living in what were known as "hostels" and participating in typical daily activities.

This concept of normalization was promoted in the United States and brought about many changes. Attention was focused on the often unconscious patterns of devaluation and discrimination against people with disabilities and how these patterns led to people being segregated, isolated and even brutalized. Also exposed was the traditional emphasis of human services on the deficiencies in people with disabilities and on finding "fixes" for those deficits.

Today, people who many years ago would have been sent away to institutions are living and participating in the everyday life of their communities. High priority is placed on training, working and recreating in the community. Still, many of these new trends in human services continue to reflect old assumptions and patterns, such as focusing on the deficiencies in people.

Futures planning seeks to eliminate the pattern of looking for deficiencies. Through a simple process, it identifies and builds on the capacities of people with disabilities and on opportunities in the community. Futures planning finds ways for people to be valued in their communities.

Randy and Elena participate in an integrated swimming class.

A NEW WAY OF THINKING

Today society's vision for persons with developmental disabilities is clearer. We have made many advances in technology, teaching strategies, legislation, medication and attitudes. This new vision supports individuals and families within their neighborhoods and communities. These values include the following, taken from **A New Way of Thinking.**[1]

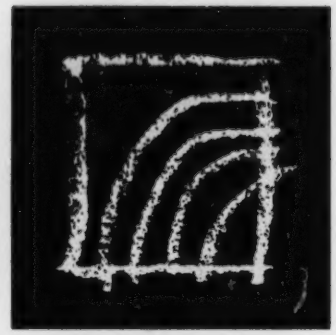
- Basing the provision of services on the informed choices, strengths and needs of individuals with developmental disabilities and their families, rather than forcing them to choose among a narrow range of pre-determined services and approaches.

- Planning and providing services based on peoples' needs and abilities, rather than providing more services than are needed, or not providing those services that are needed.

- Helping the individuals, and their family and community members to gain access to the resources available in the community—such as jobs, houses, and friends rather than replacing those resources with places populated only by human service workers and people with disabilities.

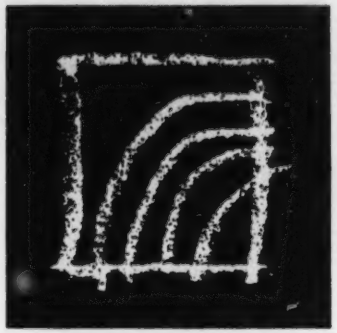
- Coordinating services around the life of the individual rather than around the needs of staff and services.

- Recognizing the abilities of ordinary citizens—children, co-workers, neighbors—to teach people skills, to help them to participate, to model appropriate behaviors and to develop relationships.



planning a future

Lisa at work in a Mexican restaurant.



planning a future

A NEW WAY TO PLAN TOGETHER

Implementing these new values and accomplishing new outcomes means letting go of service practices that support the old assumptions. For example, the traditional approach to planning for people with disabilities is focused on deficit finding. This deficit-finding is cumulative as it continues year after year. For each skill a person acquires and each objective a person meets, new deficits are identified and new goals developed. The traditional Individual Habilitation Plan (IHP) process often ends up justifying the continuance of deficit-finding and devaluation in the lives of people with handicaps.

There are at least three major problems with the traditional approach to planning:

1. It begins with an assessment process that often highlights the person's deficits. When the person is defined in terms of deficits, then the person is in constant need of services and "fixing." In this situation, the person is never ready for community life.

2. It tends to establish goals that are already part of existing programs. The plan is designed to fit the person into a particular program, even if that program is not exactly what that person needs.

3. It relies solely on professional judgment and decision-making. People with disabilities are prevented from taking initiative or directing action to affect their own lives.

Brita digs in the sand on the playground.

NEW POSSIBILITIES

Human services should provide a bridge to the community for people with disabilities. Building on people's capacities and opportunities in networks and communities allows desirable futures to be created and supported. This is the aim of Personal Futures Planning.

Personal Futures Planning is an interactive style of planning based on the assumption that there are no simple answers to complex problems. Interactive planning is a process of asking questions and learning as a group to produce actions or directions to try. This model emphasizes the **process** of planning rather than the **product.** It is a continuous problem-solving process compared to more traditional planning, such as the IHP, which may occur once a year.

Interactive planning has several distinctive characteristics:

1. It builds descriptions of capacities and opportunities in people and environments. It helps people discover the capacities that already exist within a situation.

2. It seeks ideals. People planning together are motivated by a collective vision that enables them to clarify values and find direction in complex situations.

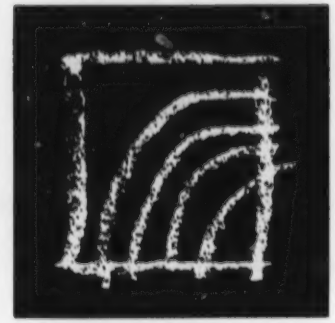
3. It brings together the people who live with the problem daily, and who are commited to learning together to be more effective in dealing with the situation. Through the group, participants learn to collaborate, reflect, clarify values, act and evaluate to find new directions.

4. It helps people invent and experiment with new courses of action. As people take action, they discover strategies that address the situations they face.

5. It inspires initiative. Interactive planning groups are guided by a vision of a more desirable future, dependent on the commitments of people to take action, and renewed by people's capacity to learn together. The groups are regenerated by their capacity to address problems, to reflect, to act and to learn.

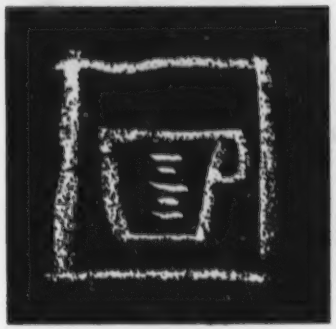
Personal Futures Planning identifies capacities and values, fosters collaborative learning and action, and encourages initiative and creativity.

There are three steps in the Personal Futures Planning process. The first is the creation of a personal profile representing comprehensive information about the individual. This is developed through a group interview. The second step is the development of a plan for the person based on the information gathered from the group. The final step is the commitment by a group of individuals to form a network of support to help the person carry out the plan.



planning a future

Dane walks to class with assistance from school staff.



finding capacities

Stacy delivers mail on her job at the University of Minnesota.

OPPOSITE: Dane and LaMar receive assistance in learning together at the computer.

FINDING CAPACITIES IN PEOPLE

All people bring important gifts to community life. This is as true for people with disabilities as it is for able-bodied persons. Too often, however, the positive characteristics and qualities of many people with disabilities have been denied or ignored. Many human services focus on deficits and negative characteristics. To some extent, the human service system depends on finding deficits in people to justify the delivery of certain programs and processes that may not really help people. The consequence of this is that the gifts and capacities people with disabilities bring to the community may be completely overlooked.

Stereotypes limit the ability of community members to see capacity—the presence of or potential to develop skills and abilities—in people. When community members perceive people with handicaps through stereotypes, then they tend to treat those people as incompetent, childish or menacing. These often unconscious assumptions close many doors to people with handicaps.

Consequently, it takes strength and determinination to find capacities in people with disabilities and to help others to see how competent these people can be when they have the opportunity to express their gifts.

Personal Futures Planning emphasizes the capacities or talents of an individual. Uncovering these qualities begins in the first step of the planning process with the creation of a personal profile.

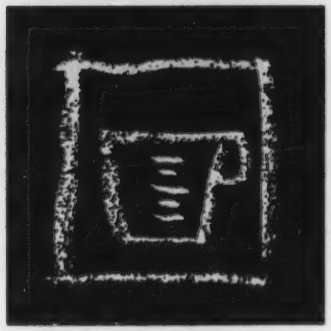
CREATING THE PERSONAL PROFILE

The personal profile is a recording of an individual's whole life—past events, relationships, places, preferences, ideas about the future, obstacles and opportunities. This first step in the planning process looks for capacities and gifts.

The personal profile is developed through a group interview at a meeting of the individual with disabilities, a few other people who care about and know the person well, and a facilitator. The term "focus person" will be used to identify the person for whom the Personal Futures Plan is being developed.

The interview, which is sometimes called a capacity search, is simply a process for getting to know the focus person and building a description of the person that clearly defines the individual's capacities and opportunities. At the meeting the facilitator interviews the focus person and a few other people close to the person. This process of interviewing is like a treasure hunt: the facilitator is looking for clues to opportunities on which a plan can be built.

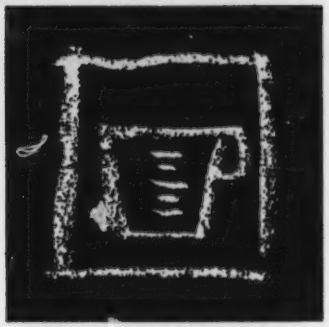
The information collected during the meeting has usually not been recorded before. It is in the memories and thoughts of the focus person and the people who have had experiences with that person over the years. The personal profile will be developed from this information rather than from written records of past assessments, goals and programs that too often emphasize the person's deficiencies.



Finding capacities

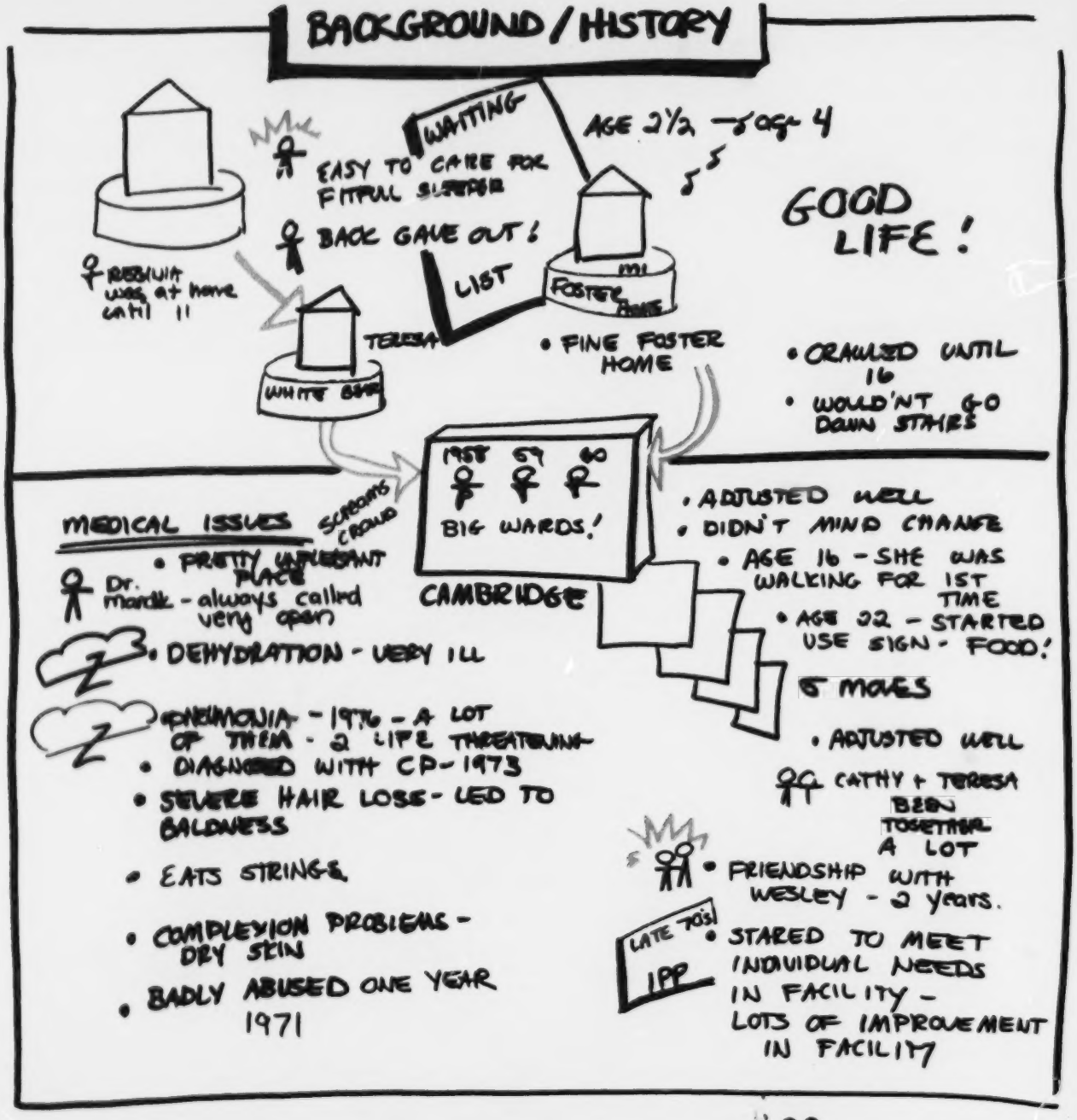
The heart of community is capacity.

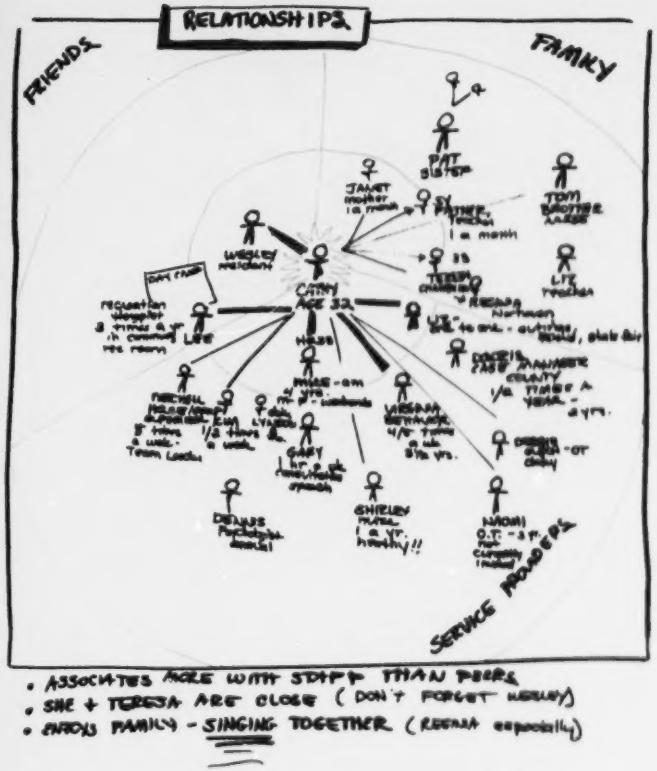
John McKnight

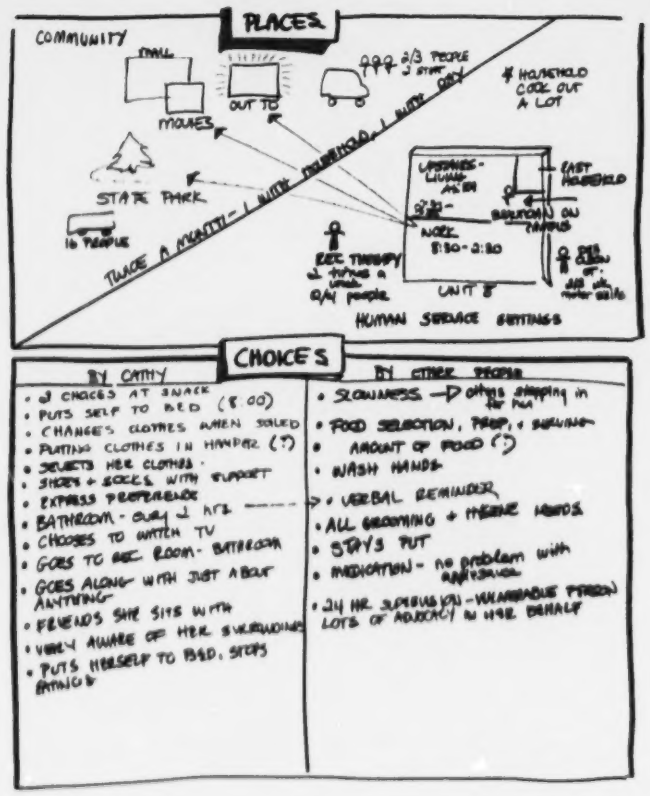


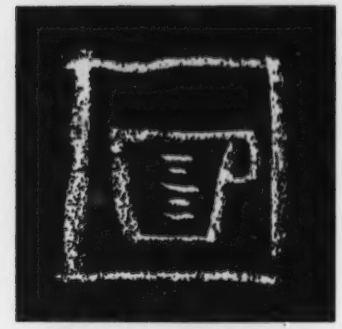
Finding capacities

BASICS: THE PERSON'S LIFE STORY


BACKGROUND / HISTORY
WAITING
AGE 2½ – 3 or 4
EASY TO CARE FOR FITFUL SLEEPER
BACK GAVE OUT!
LIST
RESIDUA was at home until 11
TERESA
WHITE BEAR
FOSTER HOME
• FINE FOSTER HOME
GOOD LIFE!
• CRAWLED UNTIL 16
• WOULDN'T GO DOWN STAIRS
MEDICAL ISSUES
SCREAMS CROWD
• PRETTY UNPLEASANT PLACE
Dr. Mardk - always called very open
• DEHYDRATION - VERY ILL
• PNEUMONIA - 1976 - A LOT OF THEM - 2 LIFE THREATENING
• DIAGNOSED WITH CP - 1973
• SEVERE HAIR LOSS - LED TO BALDNESS
• EATS STRINGS
• COMPLEXION PROBLEMS - DRY SKIN
• BADLY ABUSED ONE YEAR 1971
1958 59 60
BIG WARDS!
CAMBRIDGE
• ADJUSTED WELL
• DIDN'T MIND CHANGE
• AGE 16 - SHE WAS WALKING FOR 1ST TIME
• AGE 22 - STARTED USE SIGN - FOOD!
5 MOVES
• ADJUSTED WELL
CATHY + TERESA BEEN TOGETHER A LOT
• FRIENDSHIP WITH WESLEY - 2 years.
LATE 70's
IPP
• STARED TO MEET INDIVIDUAL NEEDS IN FACILITY - LOTS OF IMPROVEMENT IN FACILITY



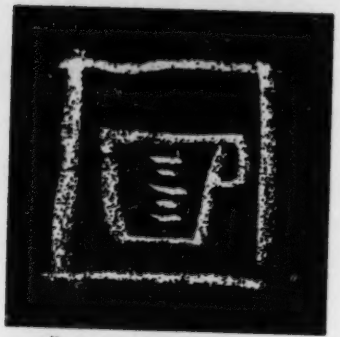

PLACES
COMMUNITY
MALL
MOVIES
OUT TO
STATE PARK
16 PEOPLE
TWICE A MONTH - I WITH FRIEND/S, I WITH STAFF
HOUSEHOLD COOK OUT A LOT
LIVING-DINING AREA
EAST HOUSEHOLD
BEDROOMS ON 2ND FLOOR
REC THERAPY
UNIT 5
HUMAN SERVICE SETTINGS
CHOICES
BY CATHY
• 3 CHOICES AT SNACK
• PUTS SELF TO BED (8:00)
• CHANGES CLOTHES WHEN SOILED
• PUTTING CLOTHES IN HAMPER (?)
• SELECTS HER CLOTHES
• SHOES + SOCKS WITH PROMPT
• EXPRESS PREFERENCE
• BATHROOM - ONLY I AT A TIME
• CHOOSES TO WATCH TV
• GOES TO REC. ROOM - BATHROOM
• GOES ALONG WITH JUST ABOUT ANYTHING
• FRIENDS SHE SITS WITH
• VERY AWARE OF HER SURROUNDINGS
• PUTS HERSELF TO BED, STOPS BATHING
BY OTHER PEOPLE
• SLOWNESS → others stepping in for her
• FOOD SELECTION, PREP, + SERVING
• AMOUNT OF FOOD (?)
• WASH HANDS
• VERBAL REMINDER
• ALL GROOMING + HYGIENE NEEDS
• STAYS PUT
• MEDICATION - no problem with ADMINISTRATION
• 24 HR. SUPERVISION - VULNERABLE PERSON LOTS OF ADVOCACY IN HER BEHALF



Finding capacities

THE PERSONAL PROFILE: BASIC INFORMATION

At the meeting to develop the personal profile, three types of information are collected about the focus person. The first is basic information: the person's background, including positive and negative experiences, major moves, critical events and current dynamics that are affecting the person's immediate future; family issues; general health; and ethnic and community ties.



Finding capacities

PERSONAL PREFERENCES

12

PREFERENCES

THINGS THAT "WORK" CREATE INTEREST, ENGAGEMENT	THINGS THAT "DON'T WORK" CREATE UPSET, FRUSTRATION, BOREDOM
• REACHES FOR HAND RAILS	• STEPPING FROM SIDEWALK TO GRASS - UNEVEN GROUND (STAIRS) (GO FOR SINGLE FLOOR)
• SUNDAY NIGHT DANCE, COUNTRY MUSIC / DANCES	• MEDICAL EXAMS - MUST HAVE RAPPORT WITH PHYSICIAN - NEED TO PREPARE DOCTOR
• STAIRS WITH RAILS	• HAVE TO GO TO BATHROOM BEFORE TALKING ABOUT IT
• FAMILY INVOLVEMENT	• ATTENTION SPAN IS SHORT
• IS HELPFUL	• PUSHES AWAY THINGS SHE DOESN'T LIKE
• FOOD RELATED - SHOWS CHOICE	• BEING IN A HURRY - NEEDS LOTS OF TIME
• SINGING - KNOWS SONGS HAPPY BIRTHDAY	• WEARING GLASSES
• ARTICULATES MORE CLEARLY WHEN SINGING	• SLOW IN DRESSING - NEEDS TIME - YOU GET TIRED OF WAITING
• LIKES TO LISTEN	• THINGS THAT TWIRL
• SMILES FOR CERTAIN PEOPLE	• CROWDS + CROWDS
• OUTINGS - MOVIES, OUT TO EAT	• NOT EATING = NOT FEELING WELL
• OUTSIDE French fries	• DOESN'T LIKE WATER, CARBO DRINKS
• BASKET BALL	• PRONE TO COLDS
• NEED TO HAVE GLASSES	• DIDN'T NOTICE CHILDREN MAY NOT SEE THINGS
• DOESN'T CRAWL - GOOD PROTECTIVE MECHANISMS - DOESN'T FALL	• LIKES TO WATCH PEOPLE
• PRETTY AGILE	• CAR RIDE
• STACKING, FOLDING, SORTING	• ROCKING (CHAIR)
• HAND MOVEMENT - PATTY CAKE - TACTILE STIMULATION	• LIKES COOKOUTS - HELPS WITH PREPARATION
• LOVES TO CLAP - FOR EXCITAIENT	• LIKES TO STIRS
• LIKES LIQUIDS - NOT ICE / CARBON	• VACUUM -
• SIT BY WESLEY	
• NEAT EATER - PRECISE	
• LOVES PRAISE !!	
• LIKES TIME TO HERSELF - STAYS IN BATHROOM	
• STAYS WITH A GROUP WELL	
• SLEEPS VERY WELL	
• WATER - Baths - enjoys water splashing	
• OBSERVANT ON OUTINGS - smiling aware	

FOCUS ON THE FUTURE

LONG TERM:

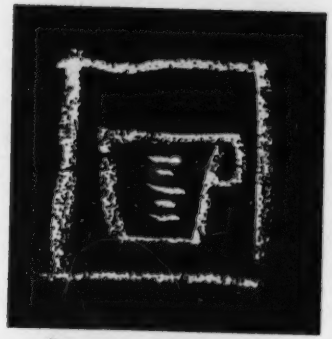
- PLANNING THE HOME + THE CARETAKER - NOT MIND DROP-IN VISITS
- FINDING AN APPROPRIATE DAY PROGRAM
- IDENTIFING SERVICE PROVIDERS
- IDENTIFY ROOMMATE —
- DESIGN PROGRAM TO INSURE PRIVACY
- BUILD IN LOTS OF FAMILY INVOLVEMENT
- IDENTIFY A LOCATION
- PERMANENCE + BACK-UP / EMERGENCY

- INSURE AVAILABILITY OF ALL SUPPORT SERVICES

- DEVELOP SIGNS FOR COMMUNITY EXPERIENCE

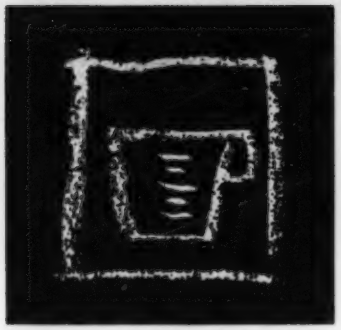
SHORT TERM:

- WORK ON THE CLASSES - especially community
- LOOK AT GOALS + OBJECTIVES - INCREASE COMMUNITY INVOLVEMENT
- LOOK AT WORK PROGRAM - MORE FUNCTIONAL WORK
- WORK ON INDEPENDENCE - GIVING HER THE TIME TO DO THINGS
- WORK ON "GO TO THE BATHROOM"
- WORK ON ADAPTATIONS
- WORK ON OPPORTUNITIES FOR FOOD PREPARATION
- MORE COMMUNITY ORIENTATION - CHURCH
- HELPING NEW STAFF GET TO KNOW HER HERE.
- CHANGE TOILET SCHEDULE TO GO THRU THE NIGHT - TRY IT 10:00-5:00 ?
- WORK ON COMMUNITY-BASED SIGNS
- PRACTICE GOING TO THE CLINIC FOR ROUTINE CHECKS, FIND OUT ABOUT DENTAL
- FIND VOLUNTEER FROM COMMUNITY TO GET INVOLVED



Finding capacities

PERSONAL PREFERENCES



Finding capacities

THE PERSONAL PROFILE: ACCOMPLISHMENTS

The second type of information collected for the profile describes the quality of the focus person's life. This information includes the person's accomplishments, routines and lifestyle patterns. One effective way of determining this information is to explore five areas of "essential accomplishments:"[2]

1. **Community participation:** Who are the people with whom the focus person spends the most time? How many are nonhandicapped? What connections and networks do they have to which the focus person could have access? People with severe disabilities usually have small social networks consisting primarily of staff members of service agencies and, in some cases, family members. To increase participation in the community they must interact with nonhandicapped community members. This can be encouraged through increased activities and opportunities to form relationships. As relationships develop, some support and assistance will be needed to maintain and improve them.

2. **Community presence:** What community environments are frequented on a regular basis? Does the focus person frequent these settings alone, in small groups, or in large groups? People with severe disabilities are often segregated by facilities, activities and schedules. A focused effort to participate in valued activities will increase the number and variety of places the individual can know and use.

3. **Choices/Rights:** What decisions does the person make independently and what decisions are made for the person by others? Growth in autonomy comes through making choices, whether they are what to eat and what to wear or what job to take and where to live. Through systematic training, even people with the most severe handicaps can be taught to make choices.

4. **Respect:** Does the person behave in ways that reinforce stereotypes? What kind of environments is the person in? What valued community roles does the person occupy each day? Respect comes from having a valued place among people and valued roles in community life. Many people with severe handicaps develop childish or aggressive behaviors or remain helpless and dependent in reaction to the way old ideas have caused them to be treated. This reinforces their less valued or devalued role as a citizen.

5. **Competence:** What skills does the person have? Which of them are needed and wanted by others? What contributions does the person make to other people's lives? Competence means having the skills to take care of oneself and do things needed and valued in everyday life with whatever assistance is required.

The information provided by considering these five essential accomplishments forms the second part of the personal profile.

Lisa sugars pastries in preparation for the lunchtime trade at Taco Bell.

OPPOSITE: Don takes a break to talk to his day program provider.

THE PERSONAL PROFILE: PREFERENCES AND DESIRES

The third type of information collected at this first meeting relates to the personal preferences of the focus person. It is the things that the individual most enjoys doing, the things that motivate and interest the person. Also included are the things that are boring, frustrating or undesirable to the focus person.

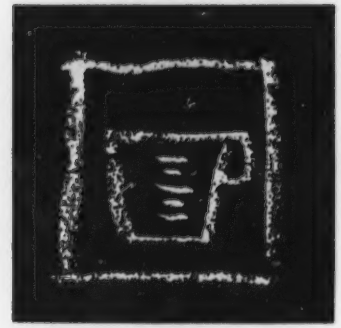
1. **Preferences:** What activities does the person most enjoy? When is the person most stimulated, engaged, motivated? What activities and conditions are most frustrating? What conditions lead to boredom, distress, depression? In what ways can positive experiences be increased and negative experiences decreased?

2. **Desires:** What images does this person have for the future? What unrecognized dreams and hopes does this person have? What does this person want in life?

PORTRAYING THE PERSONAL PROFILE

The meeting to develop the personal profile usually occurs several days before the planning meeting so that the participants have time to reflect on what was shared. The meeting, which takes about two hours, should take place in a very comfortable setting, one with which the focus person is familiar. The setting and the meeting should both be informal.

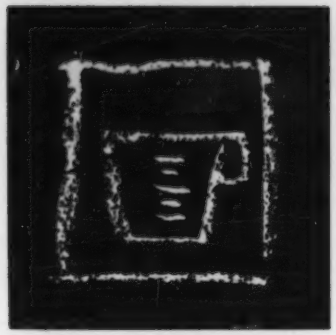
A process called "group graphics" is used to organize and portray the information with symbols. This process helps the information "come alive" for the group. The facilitator conducting the meeting interviews the group and then records all of their comments, using colors, symbols and words. The recordings produce a series of pictures and symbols that are called "maps" and illustrate the patterns of a person's life. This graphic description becomes the foundation for the futures planning. Using graphic symbols in this way helps to stimulate creativity and to encourage participation by people who have difficulty with words.



Finding capacities

I care for you, because you are mine, and I am yours.

John O'Brien



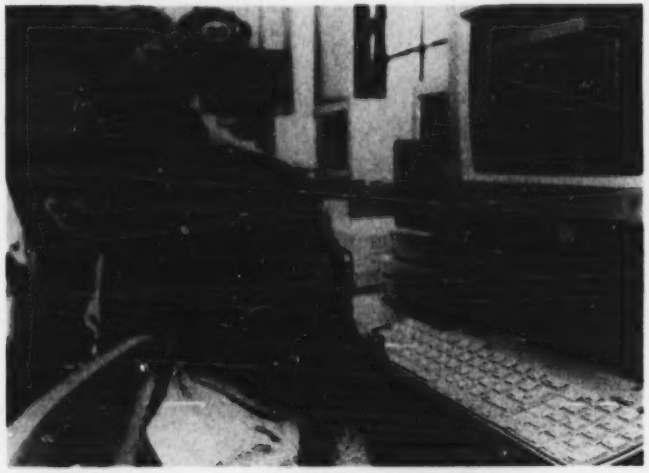
Finding capacities

EXAMPLES OF CAPACITY-SEARCH DESCRIPTIONS

The following examples of George and Alma illustrate the kinds of information collected to develop a personal profile. In each case, two sets of the descriptions are given to illustrate the differences between the capacity-search focus of Personal Futures Planning and traditional deficiency-oriented reviews. The deficiency-oriented descriptions are relatively short and emphasize negative qualities or weaknesses. The capacity-search descriptions are much longer, contain much more information and tend to emphasize strengths and capacities of both the person and the community.

George

The story of George illustrates the power of focusing on capacities instead of deficits. Tests indicate that George has a mental age of four years and three months, an IQ of less than 30, severe retardation and acute temper flare-ups. He has worked on a simulated job in a traditional workshop program that he was projected to attend indefinitely. These conclusions confirm a number of assumptions about George and the behavior and roles expected of him. The lists just below illustrate the deficiency perspective of George and the consequent assumptions about a future that meets his needs.



Tommy learns to read using a computer as part of the regular instruction program at Audubon elementary school.

A DEFICIENCY DESCRIPTION

Who is George?

- A person with a mental age of 4 years, 3 months
- A person with an IQ of less than 30
- A person who is severely mentally retarded
- A person who has "an indication of organicity, including difficulty with angles, closure, retrogression, oversimplification, and an inability to improve poorly executed drawings"
- A person with acute temper flare-ups directed at staff
- A severely disabled person

What does he need?

- A program for children
- To be protected from the world
- To learn very simple tasks and competencies
- To learn these skills separately from other people because he is so different from other people
- Highly specialized staff who can address issues of retrogression, over-simplification, etc.
- An environment in which his temper can be controlled

George accidentally met Joe, a patent attorney, who befriended him. As a result of his relationship with Joe, George's life took a new course. George got a job at E Tech as a production-line worker and learned to ride the city transit system across town to get to work. He also learned to dress more like an adult, tell time and shop in a grocery store. Developed by Joe, the capacity perspective which led to a positive future for George is illustrated below.

A CAPACITY-SEARCH DESCRIPTION

Who is George?

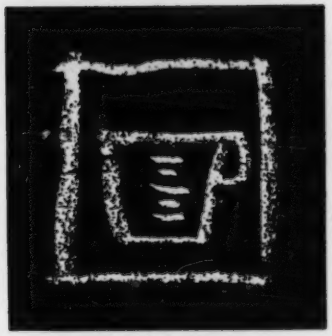
- A 40-year-old man who has missed most typical experiences and has never had a real job
- A person with little income
- A person who has been isolated all his life
- A person who has no relationships or connections to the wider community
- A person who is lonely
- A person who has little control over the direction of his life
- A person who has more difficulty learning than most people

What does he need?

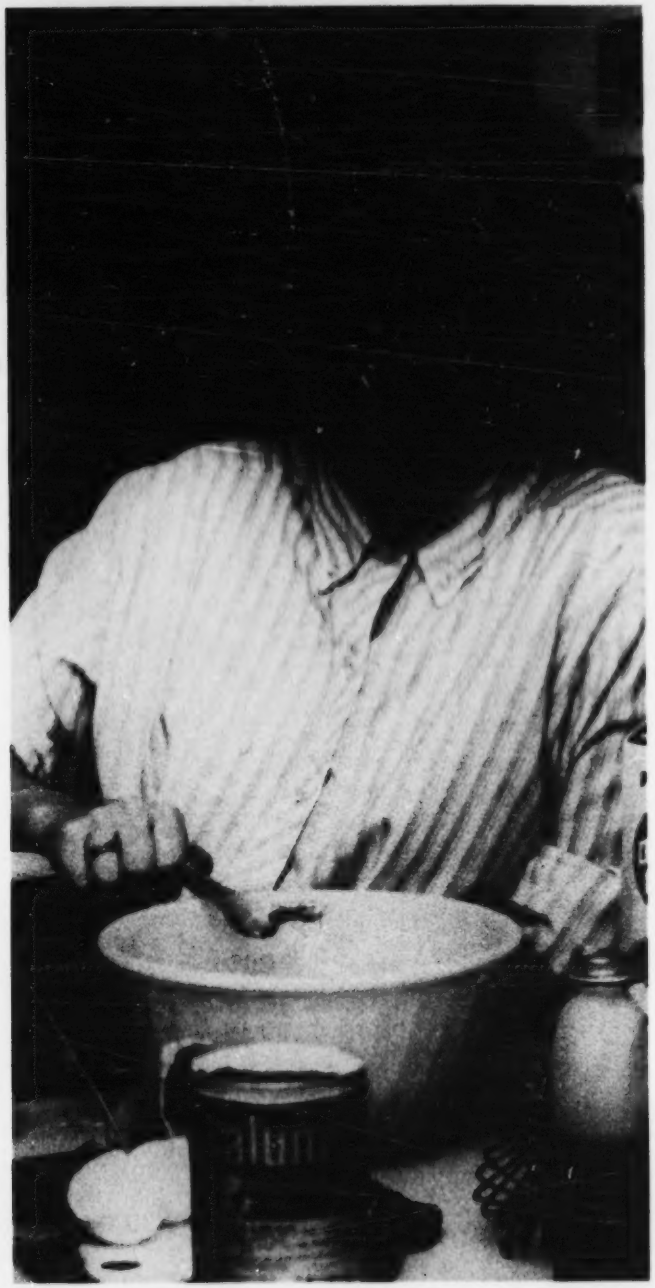
- A lot of experiences
- A real job
- A better income
- To be involved and part of the community
- Relationships with other people and connections to the community
- Friends
- A vision for the future and support in achieving it
- Someone who can speak out in his behalf
- A lot of support for learning

Finding capacities

Cathy talks with Beth Mount, a Personal Futures Planning consultant, about her plans to leave a large public institution.



Finding capacities



Denise bakes a cake with her sister at home in preparation for a family celebration.

The story of George shows how limiting assumptions can be. The pressure to see people in terms of deficits and stereotypes is great, but it can be overcome. When one sees the gifts and capacities in people and finds ways to develop them, lives can be deeply enriched. This is the purpose of the capacity search.

Alma

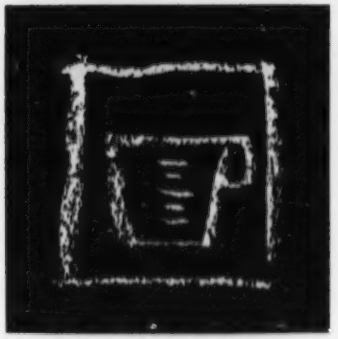
The following profiles of Alma offer another example of the two ways in which people with disabilities are described:

A DEFICIENCY DESCRIPTION

- She is a physically large 18-year-old female.
- She is enrolled in an education program for children with moderate mental handicaps.
- She is physically handicapped.
- Her right side and arm seem partially paralyzed.
- Her speech is slow and considered related to brain dysfunction and injury.
- There are signs of scars on her right arm.
- She has speech defects and lags in developmental speech.
- She has epilepsy and delayed mobility.
- There is left hemiparesis associated with brain damage.
- She scores at first-grade level on information, spelling and reading, and at second grade in math.
- Her perceptual development appears in such a simplified form that it is hard to believe that this type of reproduction comes from an 18-year-old woman.
- She has a full-scale IQ of 58, a verbal quotient of 62 which indicates functioning within mild mental retardation, and an age equivalent of 10 years, 8 months.

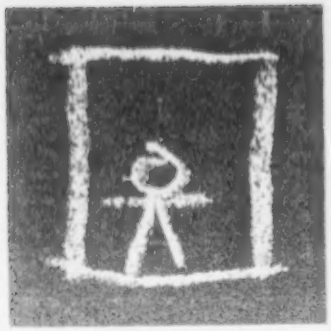
A CAPACITY-SEARCH DESCRIPTION

- **Home:** She could live independently if something were to happen to her grandmother. Alma wants to have her own apartment.
- **Health:** She is generally healthy although she has chronic allergies.
- **People:** She has 15 significant people in her network. They include her teacher, friends from school and family members. Her friendships with nonhandicapped peers have decreased over time.
- **Places:** Alma goes all over town on her own. She walks to the grocery store and other shops. She goes to the Freewill Baptist Church. She visits a lot of people. She would like to be able to get out of town more.
- **Choices:** Alma decorates her room. She chooses to visit her father. Her grandmother makes many choices for her and decides how her check is spent.
- **Respect:** Alma is congenial and helpful and has a pleasant personality. She is in the "trainable mentally retarded class" and likes to tell other people what to do.
- **Personal preferences:** Alma cooks simple meals. She gets up at 6 a.m. every day and cooks breakfast for everyone. She is a good babysitter for Maria, her little sister. She shows leadership ability. She likes to travel. She likes music and dancing. She likes "circle a word" and math exercises. She likes to help clean. She likes to watch TV. She doesn't like to wash dishes, tend to babies or read.
- **Personal images of the future:** Alma wants to acquire a skill through the vocational technical school. She wants her own apartment and a job. She would like to be able to drive. She wants to have more friends.



Finding capacities

Elena ready to jump into the pool in her after-school integrated swimming class at the Jewish Community Center.



starting small

Mary paints at a neighborhood ceramics studio.

48

49

PLANNING A PERSONAL FUTURE

The Personal Futures Planning process identifies opportunities for the future and the positive elements of the focus person's life. The vision of the future that is formed includes the opportunities and capacities that work for the focus person in their connections with family, friends, teachers or staff, the community and the resources of the service system. As time goes by, the vision of the future is continually revised as new barriers and opportunities arise.

The vision of a positive future is developed at a planning meeting. This meeting takes place after the meeting in which the personal profile was developed. The purpose of the planning meeting is to help the group clarify the preferences that the focus person has expressed and to state those preferences as goals. The group then identifies the obstacles to accomplishing those goals and develops strategies for overcoming them.

Setting up the planning meeting involves four considerations: 1) who should attend the meeting; and 2) where it should be held; 3) who should be the facilitator; and 4) how the person with the disability can best participate.

The key people in the focus person's life should attend the planning meeting. During the meeting when the profile was developed, several of these key people were identified, although they all may not have been at that meeting. These people should be invited to participate in the planning meeting and in the focus person's network. Key people usually are close friends, staff, family or others with whom the focus person spends a good deal of time. Key people are committed to the focus person and actively support a high-quality life for the focus person.

The second consideration is the environment in which the meeting is to be held. It should be informal and comfortable. A home is a good environment for making everyone feel relaxed.

Who the facilitator should be is the third consideration. The facilitator leads the group through the planning process by setting the agenda, assuring equal opportunity for all to participate, handling conflict when necessary, and recording accurately the comments and process. The facilitator needs to be a neutral, unbiased individual who is trained in Personal Futures Planning.

The fourth consideration is the participation of the person with the developmental disability. Ideally, the focus person is included in the meeting to plan his or her future. This may not be possible with people who have difficulty participating in groups or may not be able to express their thoughts and ideas in an understandable manner. It is not necessary, however, that the focus person be able to speak in order to attend the meeting.

When a focus person is not able to speak on his or her own behalf, it is a good idea to include in the meeting an advocate or spokesperson for the individual. Besides helping the focus person to communicate, the advocate can make sure the group stays centered on the person.

STEPS IN THE PLANNING PROCESS

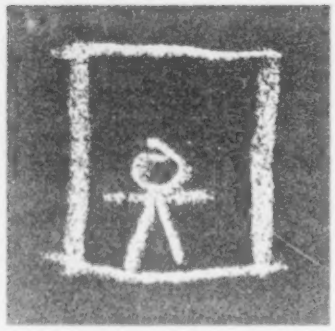
At the planning meeting, the facilitator will guide the group through seven basic steps to develop a plan:

STEP 1: REVIEWING THE PERSONAL PROFILE

The facilitator begins the meeting by reviewing with the group the information collected during the personal profile process. The group has an opportunity, at this point, to make additional comments and observations.

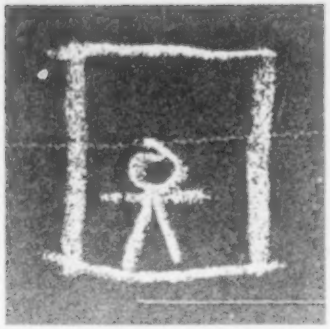
STEP 2: REVIEWING TRENDS IN THE ENVIRONMENT

Participants identify ongoing events in the environment that are likely to affect the focus person either positively or negatively. These events may be specific to the individual, such as graduation from high school, changes in the family or financial issues, or trends in the larger environment, such as the closing of a residential pro-



The future is not designed by great events, but by the small things people do wherever they are. No contribution is too small.

Beth Mount



When thinking of doing anything in community integration, think small, think face-to-face.
John McKnight

gram, the development of a new adaptive technology, or access to transportation. These events may be either opportunities or obstacles in planning and implementation.

STEP 3: FINDING DESIRABLE IMAGES OF THE FUTURE

Members of the group share their ideas about the future. This is their opportunity to think creatively. It may seem impossible to identify desirable images of the future for focus persons who cannot communicate their own ideas, but it need not be. One method a group can use to overcome this barrier is to consider what a person without handicaps but of similar age might envision. What kind of living arrangements, education, job situations, friendships and recreation do they typically choose for themselves?

As a vision of a future begins to form through this kind of brainstorming, participants are challenged to imagine ways of increasing the opportunities for the focus person to have more of the positive experiences that were identified during the profile process. The group also is encouraged to be imaginative in finding ways to link the preferences of the focus person with the opportunities available in the community.

As ideas about the future emerge from the real patterns and opportunities in the life of the person, the facilitator clusters them together in major areas. These areas might include home, work or school or other valued roles, community activities and relationships. Ideas are shared until something concrete emerges and the group agrees on the practicality of the envisioned future.

STEP 4: IDENTIFYING OBSTACLES AND OPPORTUNITIES

The group now begins translating this vision to reality. There should be one to three clusters of ideas about the future that emerge from Step 3. The group decides which area of life is the most important to work on first, which should be second, and so on.

Beginning with the first area, the group identifies obstacles and opportunities that may help or hinder making the vision a reality. The group brainstorms ideas to make obstacles become opportunities. If the obstacle cannot be overcome, then the group needs to revise the vision to accommodate it.

STEP 5: IDENTIFYING STRATEGIES

Strategies are action steps for implementing the visions developed during Step 3. The strategies should be specific and concrete. Members of the group should agree to cooperate in implementing them and make commitments to assist with that effort. They should also be careful not to take on too much at one time, remembering that the future is not designed by big events but by the small ones.

STEP 6: GETTING STARTED

Participants identify up to five action steps they can voluntarily commit to completing within a short time. It is important that many small steps happen quickly and that the group reconvene in the near future to assess the progress. If the steps are too big or take too much time to be accomplished, the focus person or group members may become discouraged and lose enthusiasm. Meeting regularly will help maintain the group's energy and commitment. The frequency of meetings will depend upon the individual situation.

STEP 7: IDENTIFYING THE NEED FOR SYSTEM CHANGE

Personal Futures Planning often leads to change in the system. The process of identifying capacities and barriers can reveal limitations and constraints of service systems that hurt more than they help. Some futures plans are not implemented because planners are unable to bring about changes in these systems. Therefore, it is very important that planners conclude a plan by listing the organizational issues that must be addressed to move forward. Strategies for changing these organizational structures can be developed in follow-up meetings.

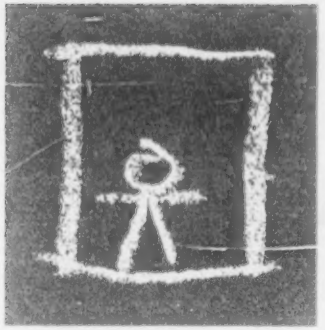
Many futures plans do not require organizational changes to be carried out. Planners do need to be aware, however, that an emphasis on organizational change is often the outcome of a futures planning meeting. Therefore, if the administrators of human service organizations plan to support the futures planning process, then they must also be willing to listen to the outcomes of a plan that requires organizational change.

IMAGES OF THE FUTURE FOR FOUR PEOPLE

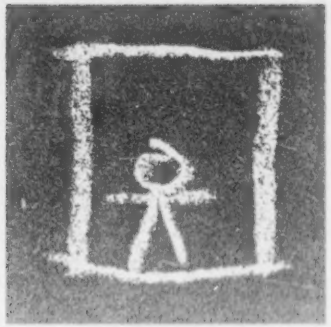
New images of the future emerge as individuals and their families discuss ways to fully express the person's capacities and interest in the community. The following examples show the diversity of images of the future people with disabilities can have.

Cathy lives in Shakopee with her mother and works part-time as a writer and editor. Her images of the future include:

1. A home in a housing cooperative so that she would not have to live in a nursing home if something happened to her mother. This home must include:
   a. A personal care attendant for at least eight hours a day;
   b. In-home emergency medical care; and
   c. A good personal support system—probably all members of this system would have apartments in the same building.
2. An artists' or writers' community in which all share their gifts.
3. A full-time job offering a health plan and other benefits.
4. Increased involvement in community life.



Jim and Harvey share a relaxing moment together.



starting small

Mary lives in a group home with seven men and women. The images of her future include:

1. Housing in an apartment or duplex with one or perhaps two roommates. This home must have:
   a. Public transportation nearby;
   b. Shopping and recreation areas nearby; and
   c. A private bedroom.

2. A full-time job as a housekeeper or in a restaurant that would be accessible by public transportation. The job would provide:
   a. Friendships and outings with co-workers, and
   b. Secure work in a valued business.

3. Increased involvement in community life, especially in church, crafts and recreation.

Matthew lives with his family in New Brighton. He is 10 years old and attends his neighborhood public school. Images of his future include:

1. Respite care and other forms of family support, including:
   a. Reliable, routine, weekend respite care;
   b. A back-up family that knows Matthew well;
   c. Respite care for emergencies;
   d. An extended summer camp program; and
   e. Low-interest loans for housing adaptations and medical services.

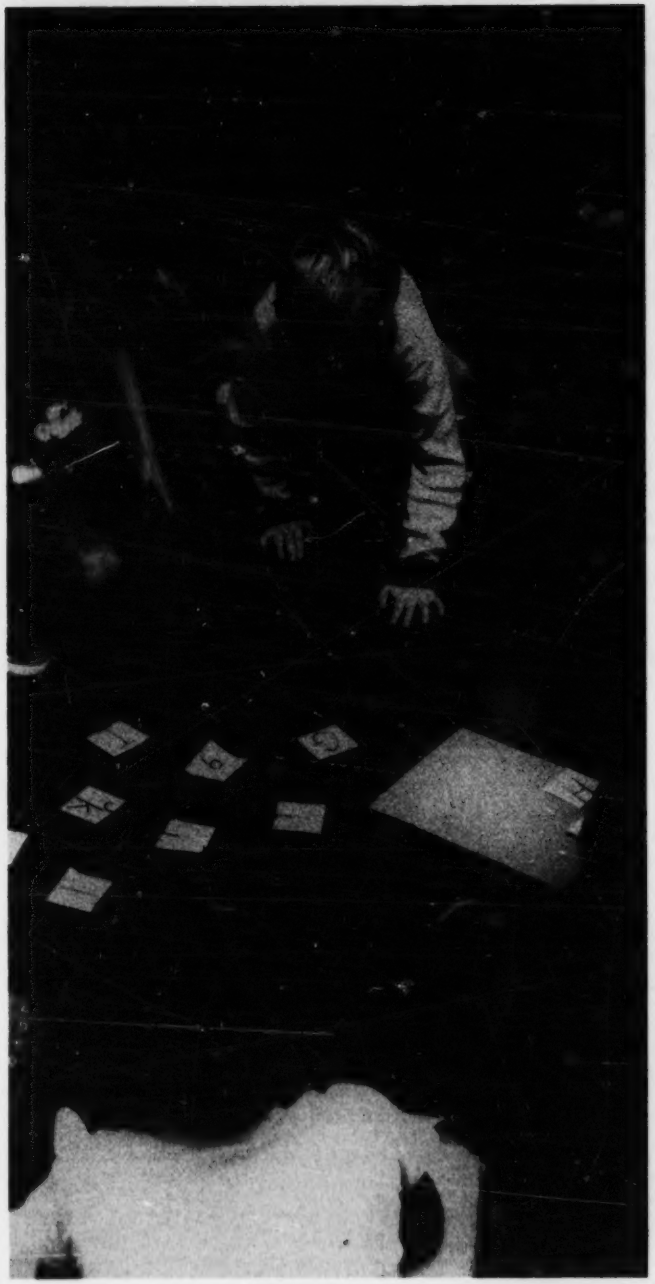
2. Recreation programs in the community such as:
   a. Saturday morning activities at the local community center;
   b. A swimming program; and
   c. A horseback-riding program.

3. Transportation so that his parents do not have to do all the driving. This service would be needed:
   a. During school hours for community learning experiences, and
   b. To and from recreational activities.

4. A permanent home so he can leave his family when he graduates from school:
   a. Close to the family home.

Mark decides which letter comes next in the alphabet.

OPPOSITE: Stretches before the integrated creative dance class begins.



Kevin is nonverbal and lives in a public institution 60 miles away from his family. He goes to a high school program on the institution campus and will finish school in two years. His images for the future include:

1. Living in the community in housing that would:
   a. Be close to his family so he can see them at least weekly, and
   b. Provide a private bedroom.

2. An alternative communication system to enable him to talk with others.

3. High school experiences such as:
   a. Attending a regular high school;
   b. Extracurricular activities;
   c. Nondisabled friends;
   d. Learning to use a computer; and
   e. Attending sporting events.

4. Involvement in community and social life, including:
   a. Places to go with friends, and
   b. Belonging to young people's groups.

5. Exposure to the world of work through summer jobs or work-study experiences.

ENSURING A SUCCESSFUL FUTURES PLAN

The process of developing a futures plan can be accomplished in one meeting, but this meeting is really just the beginning of putting the plan in place. In all of the above examples, the goals have not been accomplished yet. A plan is most likely to be successfully implemented when the following criteria are met:

1. The people forming the plan have a clear and shared appreciation of the gifts and capacities of the focus person. With this, the group can focus on opportunities in the face of obstacles.

2. People who plan together have a common understanding of a future that is very specific to the focus person and his or her community.

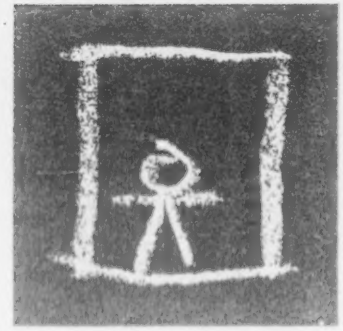
3. A group of people closely involved with the focus person agree to meet regularly to review activities, brainstorm new strategies and make commitments to act. These meetings include the focus person.

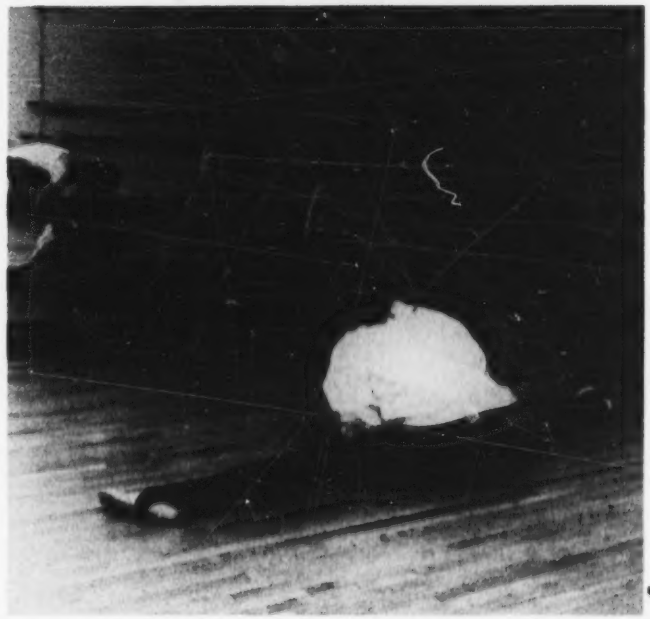
4. The group includes a strong advocate or family member who takes a leadership role in supporting group activities and continually representing the interests of the focus person.

5. The group includes a "community bridge-builder"—a member of the community or a paid person who works at building connections to the local community.

6. At least one key agency involved is committed to organizational change. The management of this organization agrees to learn from the findings of the planning group and actively seeks to remove the barriers that block the group from accomplishing its goals. Management is willing to make significant organizational changes in response to these findings.

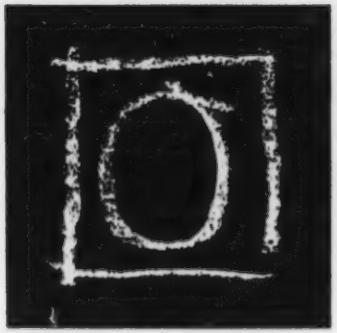
Personal Futures Planning will be a good choice as a planning strategy when these criteria can be met.





Empower people and families to jointly create solutions and opportunities.

David Wetherow



building circles

We can't fix our own lives, much less anybody else's, but we can be together, be with each other, be faithful to each other while we are going through the changes.

David Wetherow

BUILDING A NETWORK

Critical to the successful implementation of a futures plan is the presence of a group of people who meet regularly to plan strategies, solve problems and make commitments to act. This group can be made up of friends, neighbors and other people who care. This kind of group is called a "circle of support."

Some people with disabilities do not have friends or family and rely on paid human service workers for support. In these situations, the futures planning group is likely to be direct service workers and other staff members who spend a lot of time with the focus person. This group is called a "person-centered team."

Personal Futures Planning strongly emphasizes establishing a support network in the life and the future life of a person with disabilities. This network can be a circle of support or a person-centered team. How a network is developed depends on the individual involved and his or her situation.

A network of supportive people is a pre-condition for real community participation for people with severe disabilities. The network empowers the person with disabilities to make meaningful contributions to the community. The network also is a vehicle through which everyone involved in it can grow and be known for their unique contributions.

CIRCLES OF SUPPORT

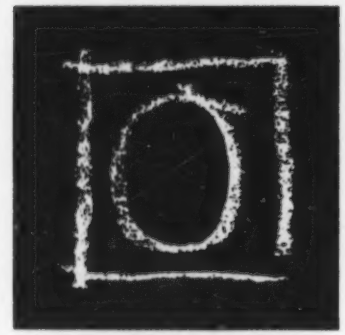
Existing relationships usually provide the basis for a circle of support for a person with a disability. Family members, friends, neighbors and others who know the person well are often part of this kind of network.

The concept of circles of support originated with Judith Snow and Marsha Forest of Canada. Snow was director of the Centre for Handicapped Students, which she founded in 1977, at York University in Toronto, Ont. When Marsha Forest first met her, Snow was 31 years old, had used a wheelchair her entire life and needed an attendant to meet all of her physical needs. Despite her position at the university, she was living in a chronic-care hospital.

As a child and young adult, Snow had participated in the usual family activities and had gone on in school to obtain a master's degree. After she left school, however, her resources for attendant care vanished, and she ended up in an instituition. This experience almost killed her.

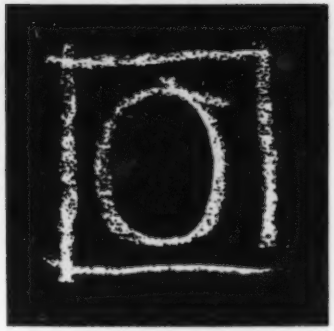
Snow's emotional and physical collapse in 1980 led to the formation, with the help of Forest and others, of the Joshua Committee. The committee was so named because its goal was to break down the wall that kept Snow imprisoned in the institution.

This group of caring people provided tremendous support to Snow and persisted in the face of serious—often bureaucratic—barriers until Snow could leave the institution. With money for attendant care, Snow moved into her own apartment and a far more independent life. She could never have managed all this by herself.



OPPOSITE: Three friends—Harry, Jim and Don.

Mark and Tina work together on a class project.



building circles

SEVEN PRINCIPLES OF NETWORKS

Out of this experience and other work, Snow and Forest developed seven principles that seem to apply to all such networks, whether they are circles of support or person-centered teams. Those principles are:

1. **Networks often form around two people who are in a very strong relationship where one is an advocate who speaks for the person with disabilities.**

   This was the case with Judith Snow. After Snow's collapse, Forest called friends together to determine and do whatever was necessary to get Snow back on the road to health.

   Such networks also form when parents are the advocates for their child with a disability. As that child moves into adulthood, however, it may become necessary to build a double network—one around the parents and the child, and one around the child and others. This allows the child to develop independence from the family. Later on, when the child is in full adulthood, a single circle usually forms, which may or may not include the parents.

2. **Strong networks usually form around a person who really wants to change.**

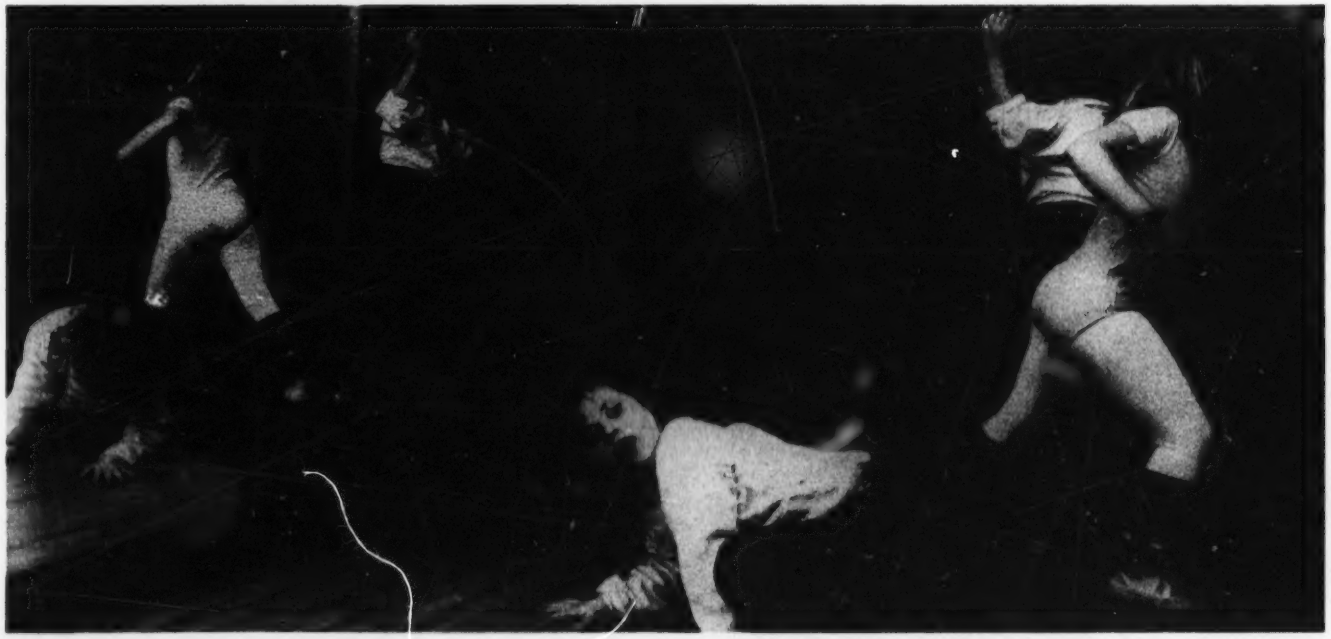
   People can make phenomenal changes in their lives when they have the support of a network. However, forcing a network on people who are content with their lives or afraid of change is useless. Meetings will always be boring, and the group will eventually fall apart.

3. **The person who is the focus of the network will grow in direct relationship to the honesty and commitment of the network members.**

   A combination of deep listening, caring, challenge and committed effort on the part of each network member helps the focus person develop his or her capacities as the individual strives to realize the vision of the future.

Community is precious. Discovering community means testing the everyday assumptions of the service world through action and reflection.

John O'Brien



4. **The purpose and direction of the network is defined by the focus person's dream.**

   The network must constantly ask the focus person: "What do you want? What do you really want?" When a network loses touch with the dream of the focus person, that person will subvert or stall the process by getting sick, behaving badly, or otherwise holding up the process until real listening happens again.

5. **The size of the network depends on how much the focus person wants to change and how fast.**

   If a network is too small, everyone will feel too much pressure. If the network is too big, people will quit because they do not have enough to do. Small networks form around little dreams; big ones are needed for big changes.

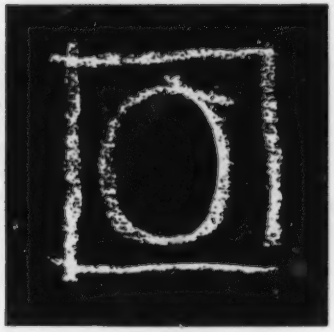
6. **Networks often come into being during a crisis.**

   A crisis sometimes occurs when a person with a disability figures out what he or she really needs instead of simply tolerating and adjusting to things as they are. This crisis can lead to the formation of a network.

   A network can form without a crisis if the person is prepared to ask for what is really needed. People often ask for what they think they can get, not what they want. Those being asked to help may feel manipulated and refuse to be involved. On the other hand, when a person asks for what is truly needed and wanted, other people feel valued and willing to commit time and energy to helping them attain it.

7. **A facilitator may be needed to help form a network or when the group seems stuck.**

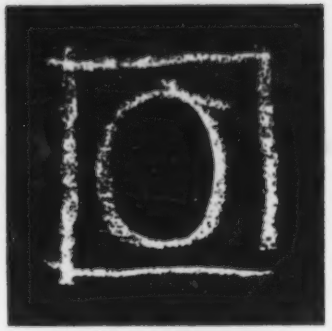
   Facilitators must be deeply committed to the value of relationships instead of therapy in a person's life. They must be good listeners, ready to love and able to challenge the focus person to express what is really needed. They also must trust network members and encourage them to value the focus person and his or her desires. Facilitators, who may be members of other support networks, must also be clear about the amount of time they can spend with each network.



building circles

OPPOSITE: Expressions of concepts in dance class.

Ceramics instructor assists Mary on her project.



building circles

KEYS TO BUILDING CIRCLES OF SUPPORT

There are five keys to forming and maintaining circles of support:[3]

1. **Focus on an individual to generate a vision.**

   A vision of what the individual desires will help to determine the structure and strategies of the plan. Start small; do not take on too much at any one time. This should ensure some early successes and movement toward more difficult steps that may be encountered along the way. Knowing the person's vision will help to keep everyone in the network on track when barriers get in the way.

   Developing a futures plan and forming a network of support is not for everyone. The focus person and the family must want to be a part of this process. They must be dissatisfied with the present, want changes to occur and be willing to help to make those changes happen.

   When creating the vision, listen to the desires and goals of the focus person and build on what the person says. Don't be critical of the person's ideas or feelings—they are important and neither right nor wrong.

   Help the individual focus on his or her strengths and abilities, and how these can contribute to making the person's vision become a reality. Describe barriers realistically: don't build them up to be more than they are because this could discourage group members. Consider ways the community can help to remove those barriers and bring the vision to life. Don't expect things to happen overnight. Good things take time to develop.

2. **Encourage and allow the focus person to develop his or her own vision and work with the person to achieve it.**

   Don't tell the focus person what is right or what is wrong about the vision. Everyone has a right to make choices about his or her life and to make mistakes.

Mary attends ceramics class with eight other women who share a similar interest.

OPPOSITE: Denise receives assistance from her sister.

Help the person see his or her own capacities and then help the individual work toward the goal or vision.

Remember that empowerment starts from the inside out and not from the outside in. People can short-circuit the empowerment process for the focus person by trying to do things for the person rather than reflecting on what the individual can do with and for others.

Remember also that professionals do not have all the answers.

3. **Work with interested friends, family and other individuals who care about the focus person.**

   Encourage the focus person or the family to invite family members, friends and neighbors to become a part of the support network.

   Look for the gifts or abilities of group members. View different ideas as ways to discover new things and to see new solutions to a problem.

4. **Find one or more members of the group who are active in community life and can help the focus person to make connections with the community.**

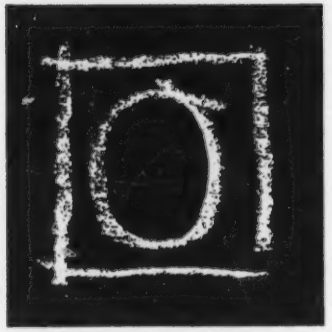
   Identify group members who are actively involved in various associations in the community and consider how those associations could help remove barriers to realizing the focus person's vision.

5. **Look outside of the group—to family, friends, neighbors and community resources—for connections by which the focus person can become more involved within the community.**

   Some connections may be through relatives and friends. Where do they work? What clubs do they belong to? What churches do they go to? How might these friends and relatives help the individual begin to get involved in the community?

   Find out who the other members of these clubs and associations are. Do they or their families have needs or interests that could be matched with the focus person's?

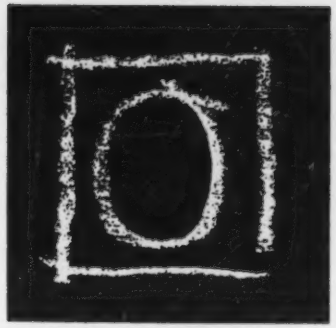
Check community publications such as newpapers, church notices and community education or recreation brochures for community resources that could assist in realizing the focus person's vision.



building circles

Community is the sense that one is part of a readily available, mutually supportive network of relationships.

John O'Brien



building circles

Foam beads provide clean indoor fun.

OPPOSITE: Brita with her friend who assists her in meeting and playing with other children on the playground in a latch-key program.

PERSON-CENTERED TEAMS

Too many people with disabilities have not had opportunities to develop relationships with nonhandicapped people in the community. Almost all of their relationships are with paid human service workers in group homes, schools, work or activity centers, or segregated recreational programs.

One study of people with mental retardation in residential care revealed that 83 percent of the residents of community facilities and 96 percent of the residents of state facilities have no social contact with nonhandicapped peers. About 42 percent of the residents of community facilities and about 63 percent of the residents of state facilities have no personal friends or special relationships.[4]

Clearly, segregated programs often prevent relationships from developing. Nevertheless, Personal Futures Planning for people in these situations can be done and can encourage involvement with nonhandicapped people. Instead of circles of support, however, person-centered teams are developed.

A person-centered team is a small group of human service workers who agree to meet regularly to review the progress of the futures plan and brainstorm new strategies. Team members should be those who know the focus person best and have the most interaction with the individual on a regular basis.

QUALITIES OF SUCCESSFUL TEAMS

Seven characteristics of effective person-centered teams have been identified by researchers. When teams develop these qualities, they are able to support dramatic changes in the lives of the people who are the focus of the plan. These characteristics are:[5]

1. **Productive meeting strategies:** Effective teams develop and maintain appropriate and efficient formats for running meetings and solving problems together. Because they conduct focused and productive meetings, they are able to meet frequently and continually redesign their strategies for action.

2. **Use of problem-solving tools and technologies:** Effective teams use group graphics, videotapes and other visualizing tools to help them reflect on their accomplishments and re-envision the next stage of activity.

3. **Focus on accomplishments:** Effective teams focus on what is working and what is not working by reviewing accomplishments at the start of each meeting. They focus on opportunities and success, and work to pursue effective strategies.

4. **Fostering of leadership skills:** Effective teams strive to develop these skills in all team members. These teams do not have one "team leader," but rather find ways to share leadership roles. In this way, team members are empowered to act and make many more day-to-day decisions.

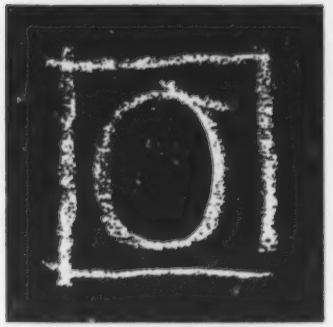
5. **Respect for and inclusion of all appropriate people:** Effective teams include all appropriate people in the planning and implementation process, particularly focus people, families, line staff and advocates. These teams work very hard to discover and build on the ideas and information provided by these key people.

6. **Development of a greater capacity to solve problems:** Effective teams develop the skills needed to solve increasingly complex problems. In doing this, they also develop the ability to change existing organizational structures and processes.

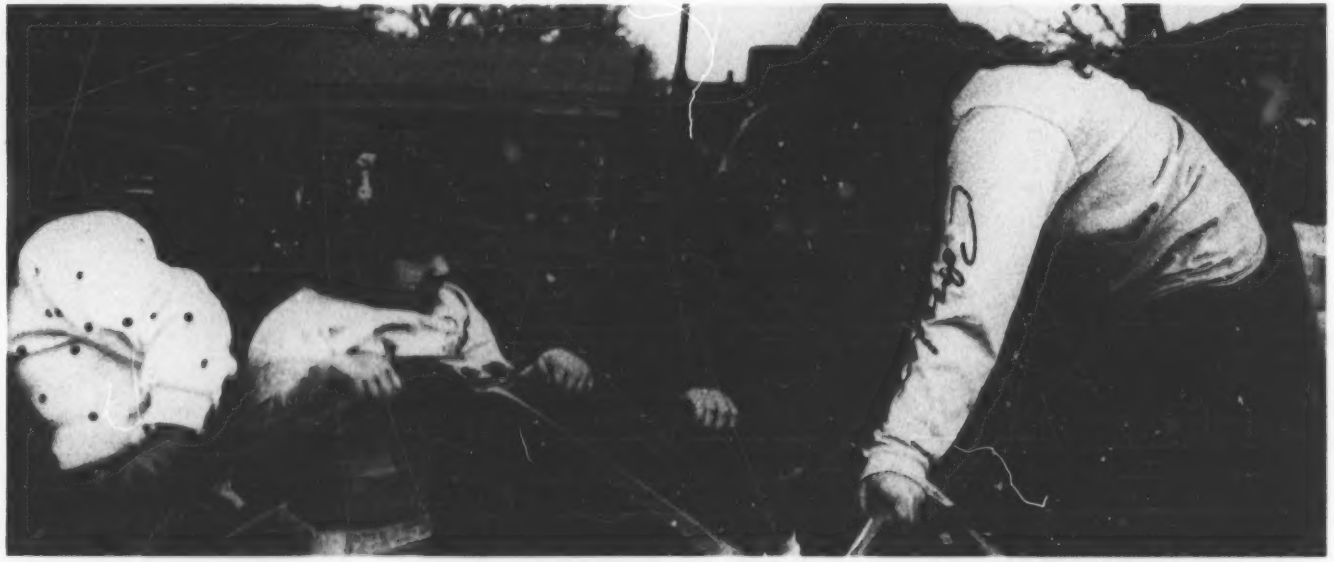
7. **Development of organizational effectiveness:** Effective teams learn to get what they need from the system in order to improve the quality of life for the focus person. These teams inform and include management and administration in their planning efforts. They receive recognition and support from management.

Once a team successfully supports change for one person, it becomes even more efficient and effective, and can expand its efforts to other individuals. Concepts and skills developed in one situation can be used in others and taught to other teams.

The person-centered team also works toward building a network of personal relationships for the focus person that goes beyond human service workers. The team can provide a bridge for people to move out of segregated programs and into the life of the community.



building circles



Bridgebuilders see the POSSIBILITIES AND CAPACITIES in people, organizations and in their own community.

John McKnight

changing systems

Share the commitment; share the vision; together we will enrich each other.

Beth Mount

PLANNING IN CONCERT

Personal Futures Planning can enhance and complement the development of other plans for the individual that are required as part of case management services.

PLANNING REQUIREMENTS IN MINNESOTA

In Minnesota, case management services for persons with mental retardation or a related condition are governed by Rule 185. This rule specifies what services are to be provided and who is involved in making decisions that affect the life of the person who receives the services. The rule, which became effective in July 1986, has the power of law.

According to Rule 185, any eligible person who requests case management services must receive them. These services include diagnosis and assessment of the individual's service needs, development of an individual service plan (ISP) and an individual habilitation plan (IHP), and the provision, monitoring, and evaluation of the services identified in the plans (see Figure 1).

The first steps in the case management process are diagnosis and assessment. They determine eligibility for medical assistance or other services under Rule 185. They are the sole basis on which individual service needs are determined and the ISP, IHP and any subsequent plans are developed.

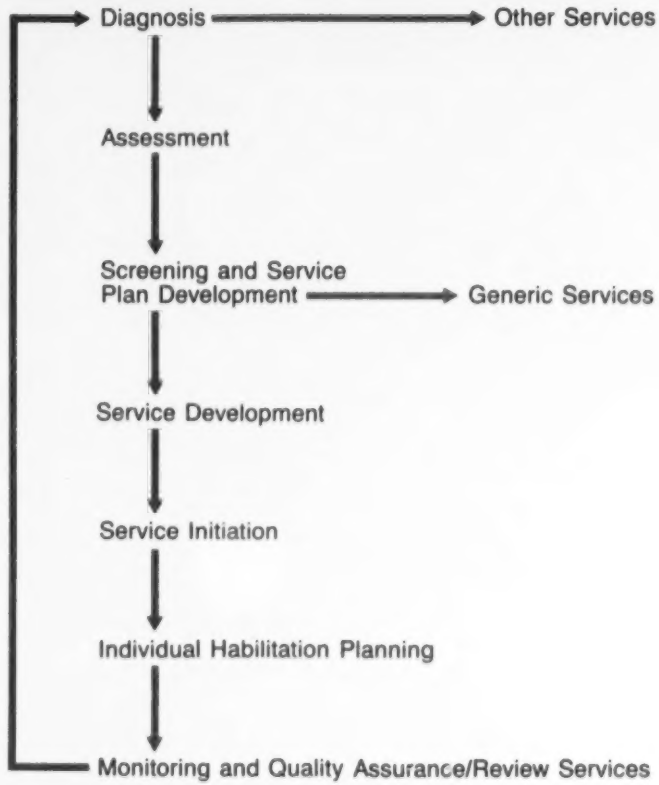
Diagnosis to determine eligibility includes testing intellectual functioning and measuring adaptive behavior. Assessment evaluates such areas as social skills, communication skills, physical development and self-care skills.

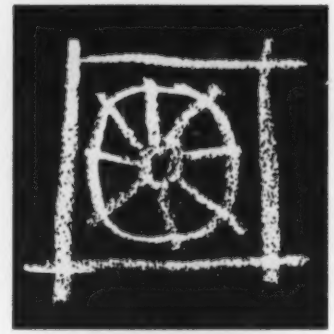
Once it has been determined that the person is eligible for case management services, a service planning team meets to decide what goals and services should be developed for the person. This statement of goals is the individual service plan, or ISP. The team is chaired by a case manager who represents the local county human services department. Other members of the team include the individual with the disability, a legal representative and an advocate, if any.

Services to help the person meet those goals are then identified. The team looks for services that are provided in the least restrictive environment possible and that ensure that the individual works and lives in age-appropriate settings. These services should involve family, friends and neighbors and ensure the health and safety of the individual. They should also allow for interactions with the general public and support the person's participation in a network of personal relationships. Finally, the team members should all agree on

Figure 1

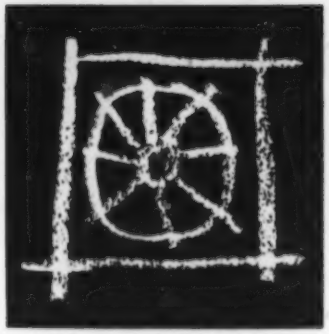
THE CASE MANAGEMENT PROCESS





changing systems

OPPOSITE: MeiLee and a classroom assistant who helps her participate in a regular classroom.



changing systems

what the services will be. The ISP must be reviewed annually. Figure 4 shows how services might be identified based on the documented needs of the individual.

Once the ISP is written, the county case manager is responsible for arranging for the services to be provided and for contracting with appropriate providers. The case manager then brings together the same team that put together the ISP and the service providers. Together they develop the individual habitation plan (IHP). This group is called the interdisciplinary team.

The interdisciplinary team reviews the assessment information, the ISP, and other relevant information and then develops a habilitation plan for the person. The IHP includes the strategies to implement the goals and services identified in the ISP and the criteria to measure progress toward attaining them. If any team member disagrees with a decision of the team, he or she can try to change it through a formal appeal process.

Services are then provided in accordance with the ISP and IHP. The case manager is responsibile for monitoring the provision of services to ensure that they meet the requirements established by the plans.

WEAKNESSES OF THE IHP PROCESS

The IHP is a legal document that specifies human service agency roles and responsibilities. Because IHPs are required for everyone who receives case management services, they may become routine and reflect a standardized, blueprint way of thinking. Common shortcomings of the IHP include:

1. The assessment process focuses on negative information and deficits and may lead to negative predictions. Descriptions may be technical, and conclusions may miss areas of need most important to the focus person.

2. The focus person's interests and desires may be ignored. Low expectations and/or stereotypic roles may predominate, especially when a majority of the team members have limited daily contact with the focus person.

3. Irrelevant short-term goals are often selected in the absence of a person-centered, relevant, long-range vision. Such goals may reinforce the use of standardized, routine procedures that occur in existing human service settings.

4. The people who must carry out the plan are usually not included in its development. This can lead to an unfair situation in which the performance of staff members is based on the results of a plan they had no part in designing.

Care is the consent of one person to live in the life of another.

John McKnight

80

81

ENHANCING THE IHP WITH PERSONAL FUTURES PLANNING

The shortcomings of the IHP can be counterbalanced with a Personal Futures Plan developed for the focus person. The ultimate goal of both planning strategies is to improve the quality of life for the person with a disability.

The example below of Ed illustrates one way the IHP was strengthened by the futures planning process. First is a summary description of Ed taken from his ISP/IHP description. This is followed by a much more extensive description of Ed from a futures planning profile. The focus person's preferences and desires identified by the profile can be incorporated into the goals and strategies of the ISP and the IHP.

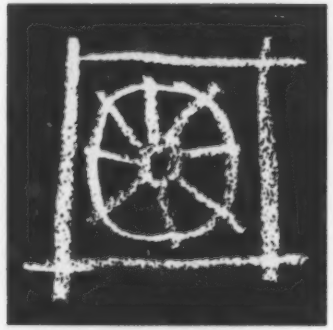
WHO IS ED?

Notes from his ISP/IHP description.

He has a mental age of three years, two months, and an IQ of 18. He has severe impairment of adaptive behavior skills and severe range of mental retardation. He occasionally becomes agitated and is usually managed informally.

He has severely limited verbal ability and is unable to comprehend abstract concepts. He learns through imitation; he has learned to unlock the soft drink machine and restock it, and to crank power motors and operate them.

Ed is 28 years old and very big physically. When he gets angry, he destroys his environment. Ed had attended a work activity program for 10 years until the staff could not control his behavior. He punched big holes in the walls of the day program he last attended, and staff members were justifiably afraid of having him in the program.



changing systems

OPPOSITE: Robert receives direction from his work supervisor.

Students with and without disabilities working on a group project.

changing systems

WHO IS ED?

Notes from his Personal Futures Plan profile

1. **Home:** Ed lives with his mother and sister in a housing project, with his extended family all around. He is likely to be taken care of by his extended family for his lifetime.

2. **Health:** He is in good health and takes a lot of psychotropic medication for behavior control.

3. **People:** He has a lot of people in his family who care about him. He has 10 relatives who visit and take an interest in him. His father doesn't spend very much time with him. Ed has two dependable sisters who could help in a crisis.

4. **Places:** Ed has a lot of freedom in his neighborhood. He visits neighbors frequently and goes to the local convenience stores with his sisters. He goes to church occasionally. He no longer uses the service center because he is "out of control" there.

5. **Choices:** Ed picks out his clothes, his food, the music he listens to, where he wants to go, and he helps shop for groceries. Other people manage his money, buy his clothes, and make major life decisions for him.

6. **Respect:** Ed dresses neatly; he is friendly and shakes hands with people. He is a very big man, with limited ability to speak. He cusses and talks to himself in a loud voice. These characteristics frighten other people, especially ones who do not know him well.

7. **Personal preferences:** Ed likes people and visiting in the neighborhood. He loves music, dancing and sweeping. He likes loading soft drink machines and operating heavy equipment. He likes to shop and to get candy and drinks. He likes to cook and can operate his stove at home. He likes to bring in clothes off the clothes line. He is good at tasks that require strength and a lot of movement.

Jim and Don work together to finish raking the lawn.

OPPOSITE: Mary Loretta shares the day's events with her housemate over a cup of coffee.

Below is a set of goals for Ed developed as part of his IHP. This is followed by another set of possibilities identified by the futures planning process. This image of the future for Ed provided a framework for developing a new IHP that more accurately reflects the futures planning vision.

WHAT DOES ED NEED?

Notes taken from his IHP

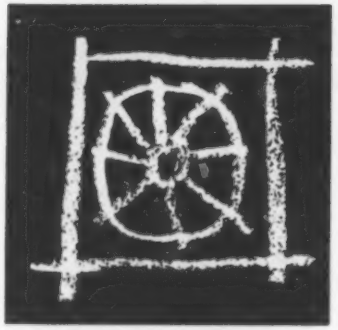
1. **Work activities:**
   a. Will operate a lawn mower correctly
   b. Will participate in three hours of basic work skills training per week

2. **Daily living:**
   a. Will wash his face and hands using soap and wash cloth before lunch
   b. Will learn to write his name by tracing over an outline

3. **Leisure/recreation:**
   a. Will participate in organized leisure/recreational activities in the community
   b. Will listen to music for 30 minutes daily

4. **Service goals:**
   a. Will receive daily transportation service
   b. Will continue medication monitoring at mental health center
   c. Will get a physical exam
   d. Will get dental services at the university dental clinic

5. **Outcomes:**
   Ed had been temporarily barred from the activity center because his behavior had become unmanageable. He had attended the activity center for over 10 years.



changing systems

Things that are powerful are uncontrolled things.
David Wetherow

changing systems

Elena waits her turn.

WHAT DOES ED NEED?

Notes taken from his Personal Futures Plan

1. **Support in being a good neighbor:**
   a. Helping other people;
   b. Bringing clothes in off the line;
   c. Being good with neighborhood children; helping older people with tasks that require physical strength.

2. **Work:**
   a. Doing tasks that require physical, active work in outdoor and social settings;
   b. Using large machines and tools.
   c. A route filling soft drink machines in his neighborhood.
   d. Opportunities to do yard work and to cut grass using a lawn mower.
   e. Use the connections that his sister and the behavior specialist have to convenience stores in the neighborhood.
   f. Use job coach to support work on a lawn crew.

3. **Having fun:**
   a. Sitting on the porch and watching the action in his neighborhood.
   b. Taking walks and going places with his family for picnics and other outdoor activities.
   c. Likes going to the local church and disco.

ROLE OF THE PERSONAL FUTURES PLAN

The Personal Futures Plan serves a different function than the IHP. It helps people to reflect on the quality of life of a person with a disability, to explore possibilities, to brainstorm strategies, and generally to reach for outcomes that are beyond the standard procedures and options of traditional services. A Personal Futures Planning meeting is voluntary and results from the concern that traditional procedures are not working or are not supporting the development of a satisfactory quality of life for the person with a disability. Futures planning requires that everyone involved in the process know the focus person and be personally concerned with and active in the implementation of the plan.

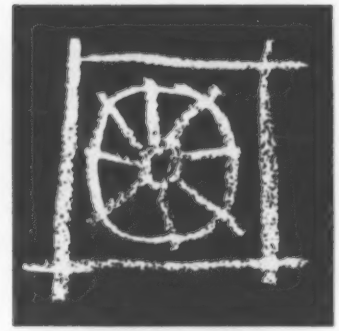
Another major difference from the IHP is that the Personal Futures Plan has no authority or force of law. Decisions made by the futures planning group are not official and need not be approved or evaluated by regulatory bodies. This enables the group to brainstorm and explore possibilities free from bureaucratic categories, restrictions and requirements. Futures planning also may include a number of people who do not work for a human services system and therefore are not required to participate or act.

While IHPs are required for all clients, Personal Futures Plans are not developed for everyone. Futures planning occurs because people involved in the focus person's life are concerned that the current service plan is not working and that simply more of what already is offered is not the answer. Futures planning takes a lot of energy and commitment on the part of each person who participates in it. For this reason alone, it may not be possible to develop futures plans for all the clients in the service system.

Futures planning typically requires a greater expenditure of time than does traditional program planning. The initial development of the plan can take four to six hours, spread over two planning sessions. In addition, the planning team usually holds hour-long monthly follow-up meetings during the initial implementation phase. Meetings to develop a person's IHP are scheduled at least annually; futures planning meetings are held as needed.

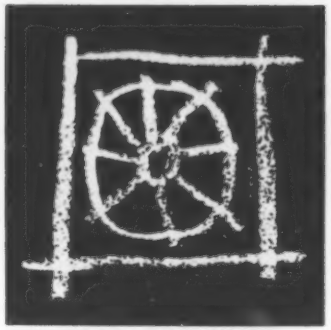
The goal of the IHP process is to develop a plan based on interdisciplinary input with exchange and participation by all team members. However, most plans reflect a multidisciplinary approach in that specific sections of the plan are "assigned" to specific disciplines, such as behavior management to the psychologist or communication objectives to the speech therapist. Assignment of such roles does not make sense in the futures planning process. Participants are involved and contribute more out of their relationships with the focus person rather than out of their specialist roles.

Futures planning is not better than individual habilitation planning, nor does it take the place of traditional planning activities. It does, however, provide access to a rich, often untapped source of information that can enhance efforts to support the person with disabilities achieve a satisfying life in his or her community. The results of the futures planning process should be integrated as much as is appropriate into the focus person's ISP and IHP.



changing systems

Robert fills soft drink containers as part of his job.



changing systems

WEAKNESSES OF THE FUTURES PLANNING PROCESS

Personal Futures Planning is an activity designed to discover and support directions and new strategies for building a satisfying quality of life for people with disabilities in their communities. However, the futures planning process has some weaknesses. Although it fosters ongoing problem-solving, it may increase the frustration of people with disabilities and direct-service staff members when there is no organizational support for implementing their ideas. Common shortcomings of the process include:

1. Profile information may focus exclusively on possibilities and ignore real limits and constraints.

2. Expectations may be raised too high. They may either be unrealistic, or there may be no path for reaching certain goals.

3. Long-range thinking may completely overshadow short-term methods and strategies. Participants may not develop immediate strategies for action. They may ignore real day-to-day issues that require immediate attention and support.

4. Staff members and focus persons may become unable to act if their new ideas are not supported by the administrators of human services programs and they are unable to affect organizational change.

5. The process can be irrelevant if the people who are planning do not have personal relationships with the focus person.

6. The process is dependent on an external facilitator. Experienced facilitators are critical to an effective and creative planning meeting, but all planning groups may not have access to such facilitators. In addition, a facilitator's own values can greatly influence the outcome of a plan.

However, the ISP and IHP process can compensate for the shortcomings of the futures planning process by providing authority and resources for the more creative vision of the Personal Futures Planning. Used in concert, futures planning and the ISP and IHP can provide a comprehensive and effective vision of the future for a person with disabilities.

We face a turning point in human services that is challenging us to let go of many past assumptions and practices. We must replace these old assumptions with new ways of thinking and new tools to help focus our attention and activities on accomplishing positive, desirable outcomes in the lives of people with disabilities. We must learn new ways to bring out the best in people and their communities. One way to discover these new directions is by listening to and building more positive futures for one person at a time. As we learn to build more desirable futures for some people, we will learn to change systems and build a stronger community for all of us.

Becky stretches her legs to warm up before dance class.

changing systems

Ben works with pegs.

Brita ponders her digging.

FOOTNOTES

[1]Governor's Planning Council on Developmental Disabilities. **A New Way of Thinking.** Available from GPCDD, 300 Centennial Bldg., 658 Cedar St., St. Paul, MN 55155. 1987. p. 5.

[2]O'Brien, John, and Lyle, Connie. **Framework for Accomplishment.** Available from Responsive System Associates, 93 Treeview Lane, Decatur, GA 30038. 1987. Chapter 3.

[3]Beeman, Pat, and Ducharme, George. **One Candle Power: Building Bridges into Community Life for People with Disabilities.** Available from Northspring Consulting, P.O. Box 93, North Granby, CT 06060.

[4]Hill, B.K., Rotegard, L.R., and Bruininks, R.H. "Quality of Life of Mentally Retarded People in Resi dential Care." **Social Work** Vol. 29. No. 3. 1984. pp. 275-281.

[5]Patterson, J., Mount, B., and Tham, M. **Final Report of the Positive Futures Project,** Connecticut Department of Mental Retardation. 1987.

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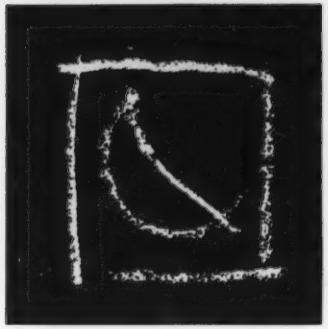

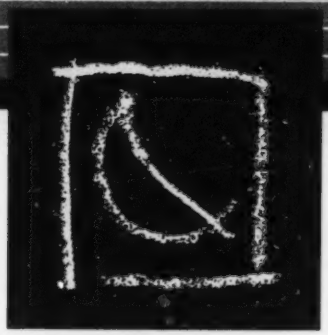

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